

# **FHI Nepal Community and Home Based Care Program Assessment**

**September 2011**



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***Submitted by:***  
**ASHA Project**  
**GPO Box 8803, Gopal Bhawan, Anamika Galli**  
**Kathmandu Nepal**

***Assessment conducted by:***  
**Center for Molecular Dynamics Nepal**

## ACKNOWLEDGEMENT

The National HIV and AIDS Strategic Plan 2006-2011 emphasizes community and home-based care (CHBC) as an essential component of treatment care and support and acknowledges CHBC as critically important for people living far from treatment and care facilities who do not have access to transport or whose mobility is otherwise restricted. The USAID-funded ASHA Project has been providing CHBC services to PLHIV and their families in the home and community since 2006. This study was an assessment of the CHBC program activities conducted under ASHA Project over the past five years.

We would like to thank USAID Nepal for their financial and technical support in conducting this study. We are also grateful for the leadership and support provided by the National Centre for AIDS and STD Control (NCASC) and for the cooperation, guidance and valuable inputs provided by members of the CHBC-Technical Working Group.

Our sincere appreciation goes to the research organization, Center for Molecular Dynamics Nepal (CMDN) and their entire team for their tireless contribution during all stages of the study process from the field work to reporting out.

We would also like to acknowledge the 13 ASHA Project CHBC partner NGOs for their valuable contribution to the design and implementation of the study: Gangotri, Community Development Forum (CDF), Asha Kiran Pratisthan (AKP), Nepal National Social Welfare Association (NNSWA), Social Awareness Centre (SAC), Junkiri, Namuna Integrated Development Council (NAMUNA), BIJAM, Naulo Ghumti Nepal, International Nepal Fellowship (INF) Paluwa, Youth Vision (YV), Society for Positive Atmosphere and Related Support to HIV and AIDS (SPARSHA), and Dharan Positive Group (DPG). Our thanks also goes to the District Public Health Officer (DPHO), District AIDS Coordination Committee (DACC) member, and ART site focal persons from the 13 program study districts and three control districts.

Very importantly, we would like to extend our special thanks to all the respondents, who gave their valuable time for the interviews and shared their personal experiences to make the study possible. Lastly, we would like to acknowledge the ASHA Project research team members especially the Strategic Information Unit and Technical Unit for overseeing the study process from study design to reporting out.

Learning from this study will be incorporated into CHBC programs to further strengthen services provided at district level as well as to inform CHBC planning and programming at the national level.

Satish Raj Pandey  
Chief of party  
ASHA Project

## **ACKNOWLEDGEMENT**

We would like to extend our sincere gratitude to USAID-funded ASHA Project for the responsibility of conducting this important study.

The study team would like to thank everyone at ASHA Project who helped in ensuring that this assessment was carried out according to the protocols and fully completed. Their inputs proved invaluable throughout the course of this study. We would like to specially thank Dr. Laxmi Bilas Acharya for his technical input and guidance. We wish to thank other members of ASHA Project, thank Ms. Dale Davis, Deputy Director, Ms. Tsering Pema Lama, Strategic Information Officer and Ms. Neera Thakur, Technical officer. We also wish to thank Mr. Satish Raj Pandey, Country Director of FHI 360 Nepal.

We are indebted to the various organizations we approached for interviews and focused group discussions for their valuable suggestions and cooperation during the field work. We gratefully acknowledge National Centre for AIDS and STD Control (NCASC) for their support and oversight. And we thank the District Health Office and Local Administrative Bodies in the study districts for providing the necessary administrative support during the study period.

The study team would like to express their heartfelt thanks to all the study participants who provided their valuable time to come for interviews and for providing the information required.

Last but not the least, the tremendous effort put in by each and every member of the CMDN field team, coding members and data analysts have all contributed to giving the final shape to this report. We sincerely acknowledge their contribution.

Study Team

Center for Molecular Dynamics Nepal

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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AKP	Asha Kiran Pratisthan
ART	Antiretroviral Therapy
ASHA	Advancing Surveillance, Policies, Prevention, Care and Support to Fight HIV/AIDS
CDF	Community Development Forum
CG	Care Givers
CR	Care Receivers
CHBC	Community Home Based Care
CS&T	Care, Support, and Treatment
DACC	District AIDS Coordination Committee
DPG	Dharan Positive Group
DPHO	District Public Health Officer
FGD	Focus Group Discussion
GO	Government Organization
HIV	Human Immunodeficiency Virus
IA	Implementing Agency
IDI	In-Depth Interview
IDU	Injecting Drug User
IEC	Information Education and Communication
INF	International Nepal Fellowship
KI	Key Informants
M&E	Monitoring and Evaluation
MARP	Most At Risk Population
MOHP	Ministry of Health and Population
NAMUNA	Namuna Integrated Development Council
NCASC	National Center for AIDS and STD Control
NGO	Non-Governmental Organization
NHRC	Nepal Health Research Council
NNSWA	Nepal National Social Welfare Association
PLHIV	People Living with HIV
PHSC	Protection of Human Subjects Committee
PEP	Post Exposure Prophylaxis

PM	Program Managers
QA/QI	Quality Assessment/Quality Improvement
QoL	Quality of Life
SAC	Social Awareness Centre
S&D	Stigma and Discrimination
SBC	Strategic Behavioral Communication
SI	Strategic Information
SPARSHA	Society for Positive Atmosphere and Related Support to HIV and AIDS
TB	Tuberculosis
TU	Technical Unit
USAID	United States Agency for International Development
VDC	Village Development Committee
WHO	World Health Organization
YV	Youth Vision

## EXECUTIVE SUMMARY

Community and home based care (CHBC) responds to the physical, social, emotional and spiritual needs of people living with HIV (PLHIV) and their families in the home and community environment from diagnosis to death and bereavement. This study was designed to assess the following aspects of the ASHA Project CHBC program in Nepal: To measure the extent of CHBC program service coverage and client retention; To assess the extent of CHBC service quality and; To measure the physical and psychosocial wellbeing of and differences between CHBC clients and non-CHBC clients. The study was carried out in 13 ASHA Project CHBC programs districts and for the control sites, three districts representing Hill, Urban and Terai where currently no CHBC programs are being conducted. Three approaches were taken: a) program data-based assessment of CHBC service coverage and retention, b) assessment of the quality of the CHBC program through qualitative interviews and assessment checklist c) quantitative questionnaire based assessment of the difference between CHBC and non-CHBC sites on physical and psychosocial wellbeing.

The program data analysis for coverage, retention and mortality from October 2006 to December 2010 among the 13 Implementing Agencies (IAs) showed varying results. The overall cumulative coverage of PLHIV on ART in the 13 districts was 44 percent and in most districts, the coverage was slightly higher for female PLHIV on ART. One of the IA had 100 percent coverage of all PLHIV on ART in their program district. The total cumulative mortality and retention were 8 percent and 86 percent respectively.

CHBC is recognized as a key component for HIV awareness, treatment, care and support. The qualitative findings revealed that the CHBC programs being run in the 13 sites continue to benefit the community and to empower and support the PLHIV clients. The services provided by the CHBC program have also enhanced the emotional and social wellbeing of the clients in all districts. The CHBC program has also been able to provide linkages to income generating activities as well as other services such as ART, medical care and counseling, which is contributing to improved quality of life for PLHIV. CHBC has also helped to reduce stigma and discrimination although these attitudes still persist.

In terms of the benefits of CHBC services, when compared with sites that do not have CHBC, the key findings show that the CHBC PLHIV on ART had better perceived psychological and environment quality of life domains. Similarly, social support was found to be very well perceived by clients using this service compared to those who didn't have access and CHBC clients were more likely to disclose their HIV status than those not served by CHBC. Some challenges remain in the CHBC program because the perceived physical symptoms were found to be greater among the CHBC group than the control group and ART adherence needs continuous monitoring by CHBC service providers to ensure it stays high.

The CHBC program has gained community-wide national support. It now needs to address issues highlighted in this report to make it even more effective. There are number of challenges and barriers that once overcome will strengthen the efficient implementation of the program at national level. This report will highlight those and provide recommendations for improvement of the program.

## I. INTRODUCTION

Community and home based care (CHBC) consists of care that responds to the physical, social, emotional and spiritual needs of people living with HIV (PLHIV) and their families in the home and community environment from diagnosis to death and bereavement.

The National HIV and AIDS Strategic Plan 2006-2011 emphasizes CHBC as an essential Treatment Care and Support component and acknowledges CHBC as critically important for people living far from treatment and care facilities who do not have access to transport or whose mobility was otherwise restricted. The National Center for AIDS and STD Control (NCASC) developed a National CHBC Training Manual in 2006 and National CHBC Guidelines in 2009.

Since 2006, ASHA Project has been implementing a CHBC program targeted to PLHIV and their families, with financial support from USAID. Currently, 13 partner NGOs are implementing the program in 13 districts through 42 CHBC service provider teams. Of the 13 CHBC programs, six of the implementing agencies (IAs) focus on providing CHBC service only while seven IAs provide CHBC service in addition to Integrated Health Services (IHS).

In addition to the CHBC services provided by ASHA Project, other organizations such as Save the Children, CARE/Nepal, United Mission to Nepal, and Sakriya Sewa Samaj, are also supporting CHBC in different parts of the country.

CHBC services are expected to encourage PLHIV to receive care in a familiar environment with participation in family affairs and with a sense of belonging in their own social groups. It is also expected that CHBC services may result in better retention in care and treatment services, reduce loss to follow up, help maintain ART adherence, improve quality of life (QoL) and become a referral link to services where they can get clinical treatment, HIV testing for children and spouses, nutrition support, schooling support, and training for income generation. Data from Cambodia, China, Malawi, Viet Nam and elsewhere indicate that CHBC contributes to improved adherence, retention in care, social support and physical well-being (Etienne et al 2007; Green 2010; NCHADS 2008; Mermin et al; Rangsimma et al 2010; Zachariah et al 2007). A recent study by Kabore et al found that CHBC was significantly associated with adherence ( $P=.01$ ) in three African countries (2010). Loss to follow-up rates were 3% for PLHIV receiving both CHBC and ART services, whereas it was 18% among PLHIV only receiving ART (Etienne et al 2007). Zachariah and colleagues found that PLHIV were more likely to remain on ART, stay in care and survive if they received CHBC services in addition to facility-based ART ( $P<.001$ ) (2007).

In 2007, a national program review of CHBC programs across Nepal was conducted. It included nine CHBC program implementers and focused on assessing the quality of the programs rather than measuring the outcomes.

This study was thus aimed at assessing various aspects of CHBC program being implemented by ASHA Project in Nepal. Furthermore, an in-depth assessment of the effect of the CHBC program was made by comparing responses from clients that receive CHBC services with those from clients that did not receive CHBC services (control). This was expected to take

into consideration the complexities of assessing an on-going program with no previous baseline with the inclusion of controls. In addition, service coverage and retention, and quality of services were assessed.

The assessment findings are expected to be used to further improve the CHBC program and make recommendations to the Ministry of Health and Population regarding further CHBC scale-up.

## II. OBJECTIVES OF THE ASSESSMENT

The primary objective of the study was to assess the coverage, quality and client-related quality of life (QoL) outcomes of CHBC services.

The proposed study included the following objectives:

- a) To measure the extent of CHBC program service coverage and client retention
- b) To assess the extent of CHBC service quality
- c) To measure the physical and psychosocial wellbeing of and differences between CHBC clients and non-CHBC clients. The following outcomes was measured:

*Primary outcome:*

Physical and Psychosocial Symptoms (Memorial Symptom Assessment Scale)

*Secondary outcomes*

- a) QoL (Quality of Life)
  - a. Health
  - b. ART adherence (self-report 7-day recall)
  - c. Health seeking behavior of PLHIV – Use of key health services and retention in care and treatment services
  - d. Perception of health status (measured by frequency of illness, self-reported weight and self-reported CD4 count)
  - e. Proportion of HIV related deaths in the HIV infected families
- b) Psycho-social
  - a. Perceived material and inter-relational social support
  - b. Disclosure
  - c. Agency (perceived self-confidence; capacity to care for self)
  - d. Perceived stigma and discrimination
- c) Prevention/behavioral
  - o Safer sex practices knowledge and application
  - o Alcohol and substance use

### III. METHODOLOGY

This study used both quantitative and qualitative methods. Since, the study population, method and data analysis varied for each study objective, this is presented separately by objective. ASHA Project team conducted the data analysis of objective 1 while, CMDN conducted the field work, analysis and interpretation of objectives 2 and 3.

#### **III.1 Objective I: To measure the extent of CHBC program service coverage and client retention**

The first CHBC program service indicator measured the cumulative coverage in terms of the number of PLHIV on ART served across the 13 program districts as a proportion of those PLHIV enrolled in ART clinics in those districts. The coverage of the ASHA Project CHBC program was conducted by collecting and analyzing the monthly data of ASHA Project from October 2006 through December 2010. The 13 CHBC program implementing agencies (IAs), their district and geographical area and start date with ASHA Project is illustrated in Table 1. The numerator used was the cumulative PLHIV who were living, and served by CHBC programs that were registered at the ART sites and currently on ART. As the exact district-wise population of PLHIV was not available, the number of PLHIV living and enrolled at the ART clinics as of December 2010 was used as the denominator which is an underestimate of the actual size of the PLHIV population. The total population of PLHIV on ART represents about 28 percent of the total national number of PLHIV diagnosed as of December, 2010. Hence, the analysis of coverage data was restricted to those PLHIV on ART only because of the restriction in the denominator. The analysis was based on the district wise total coverage and disaggregated by gender.

The second CHBC program service indicator measured the cumulative mortality rate of PLHIV clients served by the ASHA Project CHBC program from October 2006 to December 2010. The mortality data was collected from each IA for the number of PLHIV (both on ART and non-ART PLHIV) reached by the CHBC program up to December 2010. This served as the numerator in the analysis. The denominator was the cumulative number of PLHIV reached by CHBC program up to December 2010.

The third CHBC program service indicator measured the CHBC program retention rate of PLHIV clients served by the ASHA Project CHBC program from October 2006 to December 2010. The retention was assessed using the definition in the CHBC program as “those PLHIV served by the CHBC program who have been reached within 3 months of the previous CHBC visit”. As the analysis was conducted from the launch of the ASHA Project CHBC program (October 2006) to December 2010, the numerator used to explain retentions cases for that period were those PLHIV reached by CHBC programs up to September 2010, who were later reached for follow-up in the period October 2010 to December 2010 (within a three month period). However, the numerator was adjusted to include those PLHIV who were not reached between October-December 2010 but were reached later (January to July 2011) as this was a retrospective analysis conducted in 2011. The denominator in the analysis was the total number of PLHIV reached by the CHBC program up to September, 2010.

The reasons for those clients who were not retained were sought for each PLHIV client. Based on the reasons for not retained, the retention was analyzed in two ways. Firstly, a broader definition for those not retained was created to incorporate 'discontinued CHBC services' and included the following reasons for discontinuation:

- left the district (migrated to another district or country)
- out of contact
- transferred to another IA
- working as a CHBC provider
- jailed
- deceased
- chose not to receive services

Then a sub-group of those who discontinued service based on their status as out of district (migrated for work or resettled permanently) and out of contact were classified as actual client not retained for CHBC service (narrow definition). This narrow definition for non-retention was developed to exclude reasons for discontinued services for clients for whom the CHBC services had no possibility of reaching during the study period.

**Table 1. CHBC Program District and Program Implementing Partners**

S.No	Location/Districts	Geographical Region	Name of Partner	Program start date
1	Achham	Hill	Gangotri	March, 2007
2	Doti	Hill	Community Development Forum (CDF)	April, 2009
3	Kailali	Terai	Asha Kiran Pratisthan (AKP)	March, 2007
4	Kanchanpur	Terai	Nepal National Social Welfare Association (NNSWA)	October, 2006
5	Surkhet	Hill	Social Awareness Centre (SAC)	April, 2009
6	Banke	Terai	Junkiri	June, 2007
7	Rupandehi/ Kapilvastu	Terai	Namuna Integrated Development Council (NAMUNA)	October, 2009
8	Parsa	Terai	BIJAM	October, 2006
9	Kaski	Urban	Naulo Ghumti Nepal	October, 2006
10	Kaski	Urban	International Nepal Fellowship (INF), Paluwa	October, 2006
11	Kathmandu	Urban	Youth Vision (YV)	October, 2006
12	Lalitpur	Urban	Society for Positive Atmosphere and Related Support to HIV and AIDS (SPARSHA)	October, 2006
13	Sunsari	Urban	Dharan Positive Group (DPG)	March, 2007

The quantitative secondary data from program data was analyzed by ASHA Project's SI Officer using Microsoft excel. The monthly reported CHBC program data reported in PIF format from October 2006 to December 2010 were analyzed cumulatively by exporting the data into excel file. The data processing and analysis was reviewed by the SI Unit at ASHA Program along with the Technical and Program Unit.



### III.2 Objective II: To assess the extent of CHBC service quality

For the CHBC service quality assessment, several study populations were included. People living with HIV who are clients of CHBC services and their family caregivers participated in separate focus group discussions in three of the program districts representing each geographical area (Doti, Sunsari and Lalitpur districts). These two study populations were part of the quality assessment process to gauge their perspectives on the quality of care their family members have been receiving and the extent to which they are being assisted as the primary family caregiver.

Another part of the quality assurance assessment was in-depth group interviews with CHBC program managers and teams as well as key informants in the 13 program districts. Key informants were people who know about HIV and AIDS and the CHBC services and whose opinion will inform the assessment of the quality services. These included PLHIV support group leaders, District AIDS Coordination Committee (DACC) leaders and ART clinic focal persons. Table 2 illustrates the summary of interviews carried out for quality assessment.

In addition, each of the 13 program sites were assessed using FHI 360 Nepal's Quality Assessment (QA)/Quality Improvement (QI) checklist. The checklist used various methods such as staff interview, record review and observations

**Table 2. Summary of interviews carried out for quality assessment**

S.No.	Study Population	No of Interviews	No of People
1	CHBC program managers/teams (13 x 4 persons in a group)	13	52
2	Key informant (HIV Clinic manager, DACC member and PLHIV support group) interviews (13 x 3 persons in a group)	13	39
3	CHBC client/PLHIV satisfaction FGD (7 persons per FGD)	3	21
4	CHBC client/PLHIV family caregiver satisfaction FGD (7 persons per FGD)	3	21

The qualitative data from tape recordings (FGD and in-depth interviews) and field notes were translated into English into a word document. The translated notes from the qualitative findings were then analyzed by CMDN using the Atlas Ti qualitative data analysis software.

### III.3 Objective III: To measure the physical and psychosocial wellbeing of and differences between CHBC clients and non-CHBC clients.

Quantitative data was collected using a structured questionnaire to assess changes in outcomes over time among CHBC clients and compare their current outcomes to a control group. The CHBC PLHIV clients (18 years and above) on ART were compared with non-CHBC PLHIV on ART (18 years and above). Since baseline information on the measured outcomes were not available for the 13 ASHA CHBC programs, a control group (non-CHBC group) was included to quantitatively assess the primary and secondary outcomes between an intervention (CHBC) and non-intervention group (non-CHBC).

The 13 intervention sites were placed into three categories by geography and epidemic profile: 1) urban setting with HIV infections concentrated among MARPs; 2) Terai area with HIV infection primary among migrants and 3) hilly areas with primarily migrant-based epidemics (Table 1). A representative probability sample of 140 CHBC PLHIV clients on ART from the 13 CHBC programs under ASHA Project was drawn (Table 3).

Three control districts (Palpa, Chitwan and Dhanusa) were selected in consultation with CHBC Technical Working Group (NCASC and other non-government organizations implementing CHBC program). Each of the three controls represented one of the three intervention categories described above. For identification of the PLHIV who were not in CHBC services, ART clinic staff in selected districts were consulted to create a sampling frame of PLHIV enrolled in ART clinics in those districts. The control was randomly selected from three districts ART clinics and proportionally drawn based on the number of clients enrolled at each clinic. A sample of 140 controls was selected from three purposively selected control districts. Formula used for calculating the sample size for program users and control is shown in Annex 4. The distribution of randomly selected samples from the CHBC program districts and control districts are illustrated in Table 3 and 4 respectively.

The PLHIV CHBC program users who were currently on ART were compared with non-CHBC PLHIV on ART. A comparison of wellbeing between the intervention and control population was made as part of this study. Clinical data from the PLHIV interviewed in the intervention and control sites were collected from the ART clinics where PLHIV in the intervention sample and control sample were enrolled. This provided a minimum data set to compare physical wellbeing and adherence. This was also carried out by comparing retention and mortality between districts that had and those that did not have CHBC services in place. These comparisons have been published in other contexts (NCHADS 2008; Rangsimma et al 2010).

**Table 3. Sample distribution amongst CHBC districts selected for the study**

CHBC program district	Sample population size	Selected Sample
Achham	159	16
Doti	156	15
Kaikali	315	31
Kanchanpur	61	6
Surkhet	69	7
Banke	60	6
Kapilbastu	38	4
Rupandehi	66	6
Kaski/Naoul ghumti	78	8
Kaski/INF	65	6
Bijam Parsa	43	5
Youth Visiom/KTM	119	12
Sparsha/Lalitpur	126	12
Sunsari	58	6
<b>Total</b>	<b>1413</b>	<b>140</b>

Similarly a sample of 140 was designed for the control group. Controls were selected from Palpa, Chitwan and Dhanusa districts. Table 4 provides the details of the controls selected in the sample by districts.

**Table 4. Sample distribution amongst CHBC districts selected for the study**

Control district	Sample population size	Selected sample
Palpa	78	38
Chitwan	154	63
Dhanusa	107	39
<b>Total</b>	<b>339</b>	<b>140</b>

The quantitative data collected from the client outcome survey was analyzed using statistical software SPSS. Double entry system was used for entering the quantitative data to reduce entry errors and frequency distributions, cross tabulations and regression analysis were used to establish findings. ASHA Project SI team monitored the data entry, cleaning and analysis process during the study.

#### **III.4 Ethical considerations**

The study was conducted in compliance with all human rights and ethical standards required by health researchers conducting studies among human subjects on sensitive issues such as HIV and AIDS. The study protocol was approved by the Nepal Health Research Council (NHRC) and FHI 360's ethical review body, the Protection of Human Subject Committee (PHSC). The field work of the study was initiated only after both approvals were obtained.

Informed consent was obtained from all interviewees prior to the interview. In the case of CHBC clients/PLHIV or family caregivers oral informed consent and a signed witnessed consent were obtained. The interviews were conducted at a safe and confidential place agreed to by the study participants. During the consent process, it was made clear to participants that they were free to refuse participation, and that if they decided to participate, they could stop at any time during the course of the interview, if they wanted to. Particularly, interviews with CHBC clients and PLHIV were conducted at their homes, if they felt comfortable. Interviewers were not associated with local HIV service providers supported by ASHA Project or the government.

Best efforts were made to minimize risks associated with study participants. No names or personal identifiers were used for the data collection questionnaires or in any other documents from PLHIV and their caregivers but consent was obtained from all participants.

All PLHIV and caregivers of PLHIV participants were compensated for their local travel cost while participating in the study.

### **III.5 Toolkit Development**

#### *QA/QI checklist:*

The QA/QI checklist tool was developed based on the tool kits used in the 2007 study carried out by ASHA Project. The final checklist is available in Annex 3.6.

#### *Guidelines for FGD:*

These guidelines focused on quality assessment information to be collected from each of the two groups of FGD: CHBC client and CHBC caregivers. The criteria for selecting participants for FGD were as follows:

- 1) PLHIV of 18 years or above who have been using CHBC services provided by the ASHA Project supported programs for the last six months or more.
- 2) Caregivers of PLHIV of age 18 or above who has been receiving CHBC services provided by the ASHA Project supported programs since last six months or more.

The details of the guidelines are presented in Annex 3.4 and 3.5.

#### *Guidelines for In-depth group Interview:*

These guidelines focused on quality assessment information to be collected from each of the two groups: Program manager/service providers and Key informants.

The criteria for selecting the Program managers and service providers for the in-depth group interview were: Individuals who are CHBC program managers and service providers (PLHIV or non-PLHIV) and who have been working in this profession for at least three months.

The criteria for selecting Key Informants for the in-depth group interview were individuals belonging to following three groups: ART focal person, District AIDS Coordination Committee (DACC) Coordinator and PLHIV group member.

The details of the guide lines are presented in Annex 3.2 and 3.3.

#### *Standard quantitative (client survey questionnaire) development:*

The quantitative questionnaire used for objective three, was developed using the pre-test palliative care questionnaire used by FHI 360 Vietnam with the addition of a QoL component from WHO (WHOQOL-BREF). Key indicators included, among others, health, psychosocial wellbeing, behavioral aspects, quality of life indicators. Furthermore, regular meetings were carried out with ASHA Project personnel to ensure that the toolkits were adequate and clear. All the tool kits were translated into Nepali and the Nepali version was used in the field. The questionnaire is presented in Annex 3.1.

### **III.6 Hiring and Training of staff**

Field researchers and field assistants were hired in Kathmandu by CMDN based on their previous experience with CHBC and/or HIV related research work. Most of those were public health graduates or higher. Local motivators were hired locally in each of the sites.

A total of 12 field staff were hired to cover 13 CHBC and 3 control sites. Local motivators were hired locally depending on the work load at each site. The vocal motivator's role was to assist the field researchers in identifying and engaging clients for interviews. A two-day training was organized to familiarize the staff with CHBC protocols and the toolkit implementation. Trainers were invited from NCASC, ASHA Project and NAPN community.

### **III.7 Piloting of study tools in the field settings**

All the tool kits were translated into Nepali and were field-tested as a pilot with SPARSA for clarity in the language used and order of the questions asked. Minor changes were incorporated, mostly on phrasing.

### **III.8 Field placement**

Each field team (FTs) in general consisted of two field researchers (FRs), and one local motivator (LM). In some instances, the field assistant (FA) was hired to assist the field team. Each FT was responsible for at least two districts and in some cases, three districts. The FTs looked after both control and CHBC districts. Six different FTs were engaged for field research. LMs were hired locally and trained to assist in networking with the PLHIV community and local NGOs.

### **III.9 Monitoring and supervision**

During the entire field work process, staff from CMDN, ASHA Project and NCASC regularly monitored the six teams. This included all the key personnel of the program including country director of ASHA Project and the senior medical officer from NCASC. A monitoring checklist was utilized for this purpose to efficiently and systematically monitor the field work of six different teams. Both Kathmandu and outside Kathmandu teams were monitored at least twice during the field survey duration. A supervision team reached the entire study group for quality assurance. Frequent supervision resulted in enhanced quality of results. The mechanism for communication by CMDN with field staff was in place in the form of daily phone calls to the FT and recording of their activities.

ASHA Project Senior SI Advisor and SI Officer monitored the data entry, data cleaning and analysis process in order to ensure the quality of the data was maintained.

### **III.10 Data Processing and Analysis**

Quantitative secondary data from program reporting was analyzed by ASHA Project's SI Officer using Microsoft excel. The monthly reported CHBC program data reported in PIF format from October 2006 to December 2010 were analyzed cumulatively by exporting the

data into excel file. The data processing and analysis was reviewed by the SI Unit at ASHA Program along with the CHBC program technical officer and program officers.

Electronic software - Atlas Ti was used for qualitative data analysis. Quantitative data collected from the Client Outcome Survey was analyzed using statistical software SPSS. Double entry system was used for entering the quantitative data to reduce entry errors and frequency distributions, cross tabulations and regression analysis were used to establish findings.

## IV. RESULTS

### IV.1 Objective 1: To measure the extent of CHBC program service coverage and client retention

#### *CHBC Assessment: Program Data Analysis*

The Program data analysis included the analysis of the cumulative program coverage, cumulative mortality and cumulative retention since the start of the CHBC programs implemented by the 13 IAs.

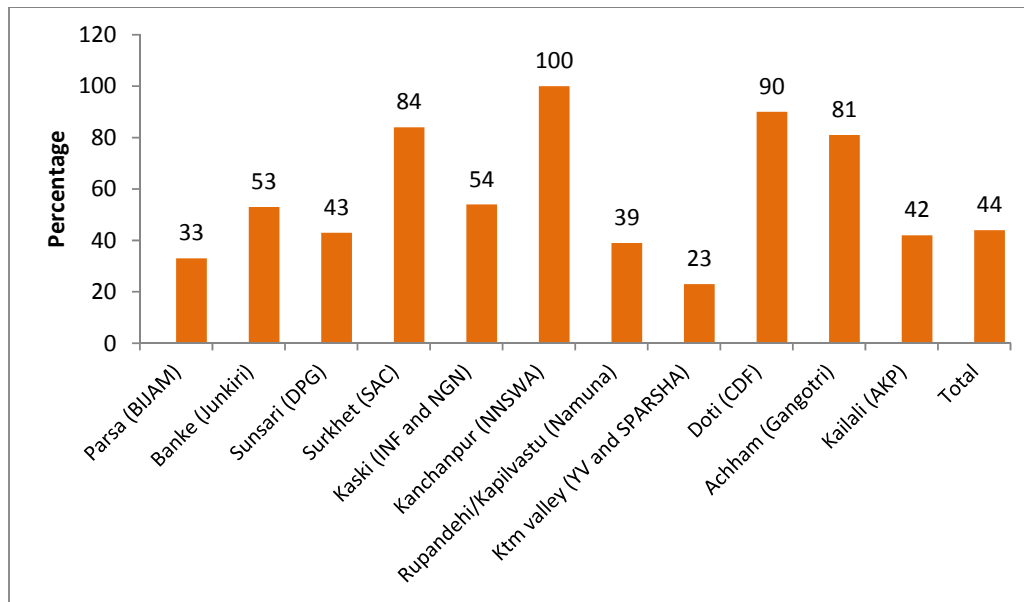
Program coverage analysis:

The CHBC program service coverage was analyzed for only around 44 percent of the total CHBC clients served up to December 2010, as the analysis was limited to those CHBC PLHIV clients on ART. The denominator required to measure the coverage was PLHIV on ART registered at the district ART sites up to December 31, 2010. Coverage was defined as those PLHIV who were alive and on ART and were CHBC clients served by ASHA Project. Since the denominator was the cumulative number of living PLHIV on ART who were registered at ART sites in the year 2010, the numerator did not count those CHBC clients who were reported to have died up to December 31, 2010. The coverage analysis provides information related to the level of CHBC uptake across the 13 program districts as a proportion of those enrolled in ART clinics in those districts.

The data analysis of the total coverage by IAs within each district is illustrated in Figure 1. Overall, the findings show that the total coverage in all 13 program districts by the 13 IAs is 44 percent. The districts with coverage of 80 percent or more were Kanchanpur (100%), Doti (90%), Surkhet (84%) and Achham (81%) in decreasing order, which are all districts of the Mid and Far-Western regions. The lowest coverage was in Kathmandu valley (Kathmandu, Bhaktapur and Lalitpur districts) at 23 percent, which may be attributed to only having two CHBC programs in three very densely populated districts, Youth Vision targets PLHIV with a focus on IDUs in Kathmandu and SPARSHA targets PLHIV mainly in Kathmandu and Lalitpur districts. Secondly, until 2010, Kathmandu valley had four ART sites, Sukra Raj Tropical and Infections Disease Control i.e. Teku Hospital, (the first and largest ART site), Tribhuvan University Teaching Hospital, Maiti Nepal and SPARSHA. PLHIV living in other neighboring districts are accessing their ART medications from these ART sites in Kathmandu valley and hence the denominator may consist of PLHIV from outside of Kathmandu valley and may also be subject to double counting due to PLHIV taking ART from multiple ART sites within Kathmandu valley. BIJAM had the second lowest coverage at 33 percent. This can be attributed to their program coverage area which is limited to the Birgunj municipality and the surrounding Village Development Committees (VDCs).

These findings suggest the need to reassess the availability of services in the districts with restricted coverage areas for increasing access to services for unserved PLHIV living in rural or densely populated areas.

**Figure 1. Total coverage of PLHIV on ART served by CHBC programs by district (October 2006-December 2010)**

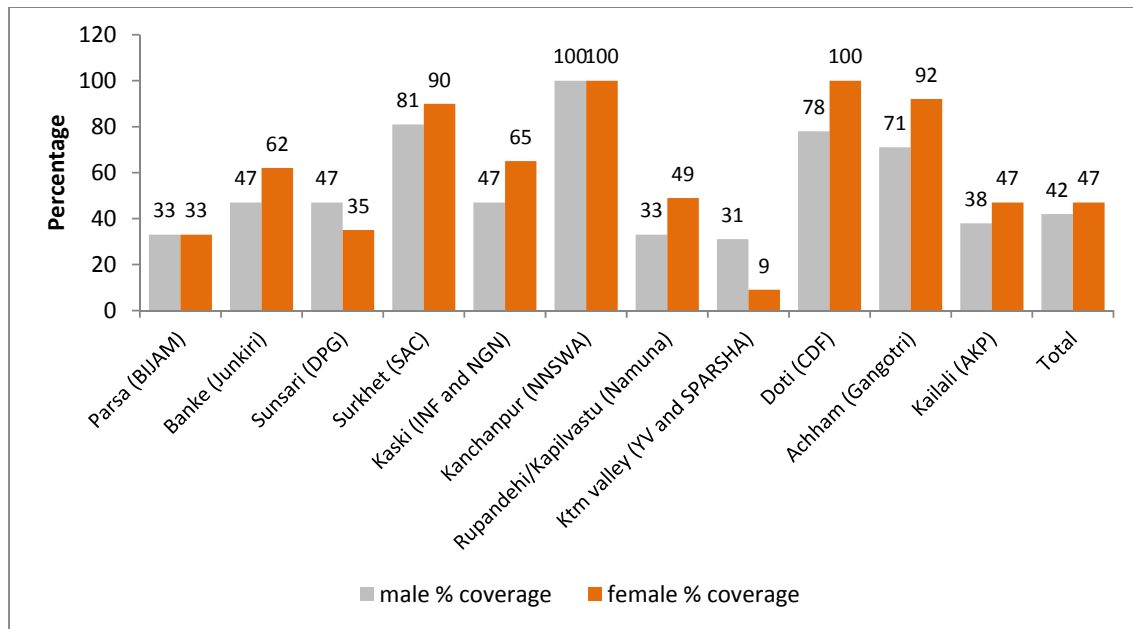


According to the coverage data analysis by gender illustrated in Figure 2, the total coverage is slightly higher for females (47%) than males (42%). The majority of the districts had a higher coverage of female PLHIV on ART and most of them are widows whose husbands died from AIDS. One of the exceptions is Kathmandu valley where the male coverage is more than three times higher than that of the female coverage and this is mainly because the CHBC service provided by Youth Vision focuses on PLHIV who are or were mainly male IDUs. Coverage analysis disaggregated by gender helped assess the gaps in coverage in the programs. For example, in Doti district, the CHBC service providers from CDF have 100 percent coverage of female PLHIV on ART and only 78 percent coverage of male PLHIV on ART. This shows that the high total coverage by CDF in Doti district was because of the full coverage of female PLHIV on ART and the program can further improve coverage by increasing their enrollment of male PLHIV on ART.

The situation is similar in Achham, Surkhet, Banke, Kaski, Kailali, and Rupandehi and Kapilvastu districts. The higher coverage of female PLHIV on ART compared to the males may indicate that the female PLHIV on ART are more easily reached and/or that male PLHIV on ART are more likely to migrate to India or other districts in search of work. Further qualitative studies and secondary analysis of the quantitative data on CHBC clients will be required to assess the reasons for the difference in CHBC program coverage between men and women.



**Figure 2. Gender wise coverage of PLHIV on ART served by the CHBC program by district (October 2006-December 2010)**



The mortality rate among PLHIV clients served by ASHA Project IAs providing CHBC services is illustrated in Figure 3. Since the launch of the CHBC program in October 2006, the total cumulative mortality rate among the 13 IAs, as of December 2010, was 8 percent. The 2009 national estimated average number of deaths per year was 4,701 in an estimated HIV population of 63,528, which results in annual mortality rate of 7.4 percent (NCASC, 2010). Seven of the 13 IAs had mortality rates above the total of 8 percent with the highest mortality in NNSWA (13%) followed by Junkiri (12%) and SAC (11%). AKP in Kailali district had the lowest mortality rates at 4%.

The higher mortality rates were found among the IAs with the highest coverage such as NNSWA and SAC. The CHBC services provided should aim to reach PLHIV clients as soon as possible after their HIV diagnosis to ensure early treatment, care and support.

**Figure 3. Cumulative mortality rate among PLHIV clients served by the CHBC program by district (October 2006-December 2010)**

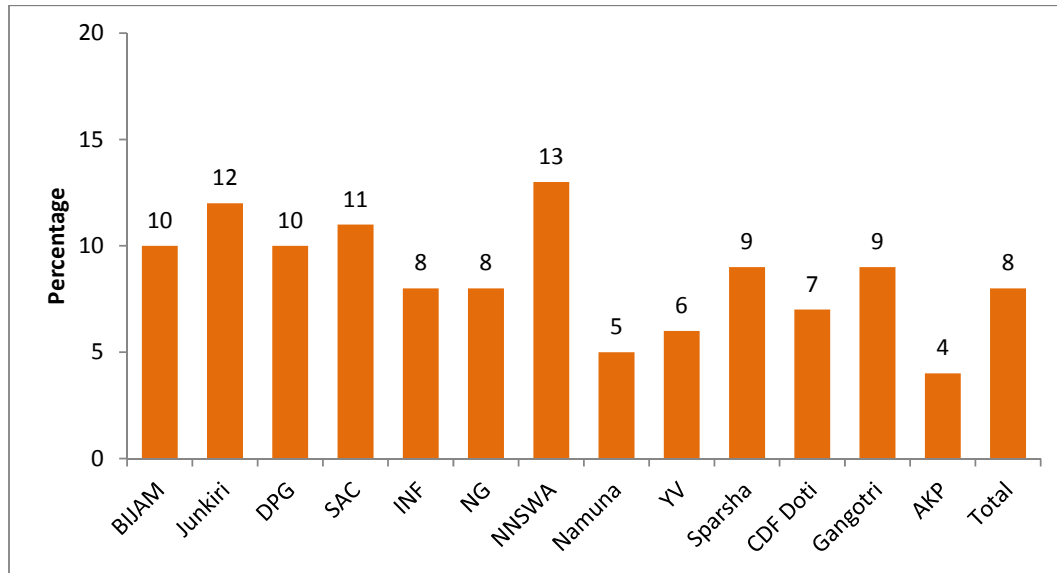
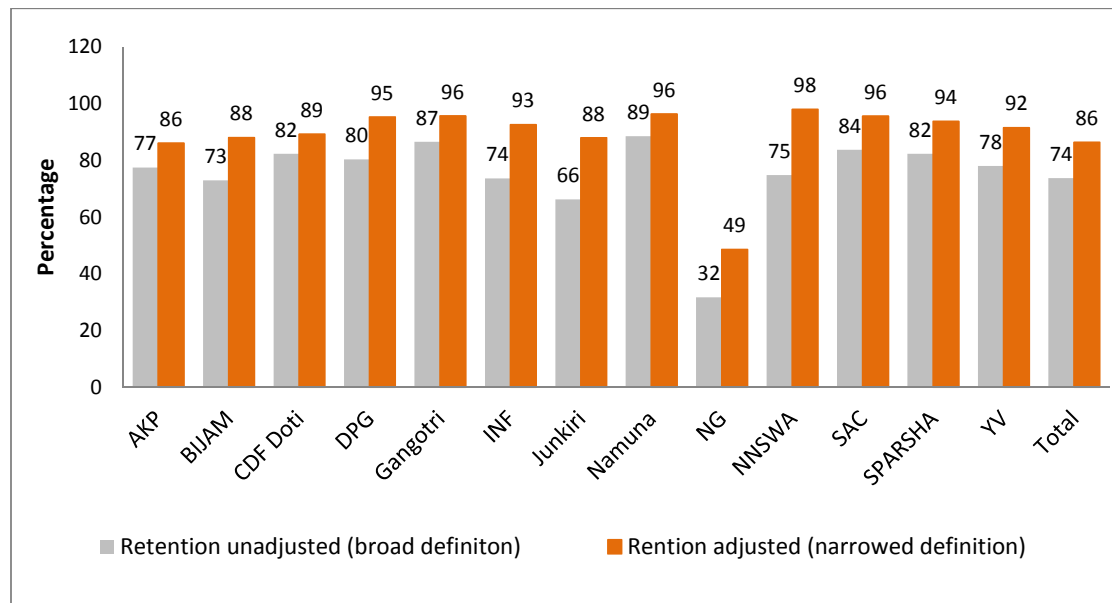


Figure 4, illustrates the proportion of PLHIV clients retained in the CHBC programs (adjusted and unadjusted). The unadjusted retention excludes all those clients that were not retained for the various reasons under discontinued services (broad definition) mentioned in the methodology section. The adjusted retention excludes only those PLHIV not reached because they are out of contact or out of district (narrow definition). The total cumulative proportion of unadjusted retention and adjusted retention were 74 percent and 86 percent respectively. Naulo Ghumti was an outlier with the least cumulative unadjusted retention (excluding discontinued services) and adjusted retention at 32 percent and 49 percent respectively. A large proportion of the PLHIV served during the initial phase of the CHBC program by NG were PLHIV from neighboring districts who were then based in care homes in Kaski and receiving ART from Western Regional Hospital. These PLHIV were reached through the Community Based Care component of the CHBC program and once they returned to their own districts, they were out of contact and hence were not retained in the program. For all the IAs, the proportion of actual retention increased after narrowing down the criteria for retention. NNSWA, Gangotri, Namuna, SAC and DPG had the highest adjusted retention at 95 percent or above.

**Figure 4. The proportion of PLHIV clients retained in the CHBC services (October 2006-September 2010)**



**Recommendations:**

- Strengthen monitoring of LFU, mortality and coverage by IA is required to manage for gaps and program alignment.
- Increase coverage area in districts with lower coverage, if PLHIV are not being reached by another program.
- Strengthen the reporting of deaths and lost-to-follow-up in the monthly reporting by IAs.
- Strengthen the coordination between CHBC teams and ART sites for referral of PLHIV clients on ART to CHBC service sites and regular referral of CHBC PLHIV clients to ART sites.
- Adjust for double counting at ART sites at national level, for example, introduction of unique IDs at national level.

**IV.2 Objective 2: To assess the extent of CHBC service quality**

**Part 1: Quality Assurance/Quality Improvement (QA/QI) checklist assessment**

A Quality Assurance/Quality Improvement (QA/QI) was carried out in all thirteen program district sites using a checklist developed for the purpose. The checklist was divided into the following sections: (i) Training; (ii) Program Planning and Approach; (iii) Management and administration; (iv) General operational issues; (v) Infection control practices; (vi) CHBC records and client registration; (vii) CHBC supplies ; (viii) Home based Care visits (planning, visits and observation); (ix) Community Services and ; (x) Monitoring and evaluation. The researchers completed the checklist based on their observations and interactions with the IA management and CHBC team members. All findings reflect the observations and on-site

circumstances at the time of the visit. The researchers paid attention to the accuracy of their reporting and efforts were made to minimize subjectivity and bias.

The findings from assessment are presented according to the checklist sections. The IA wise quality assessment results are presented in Annex 1.

### **Training**

All the IA CHBC teams had received basic CHBC training from ASHA Project based on the National CHBC training manual. The CHBC teams in all but two IAs had not received the CHBC refresher training. NNSWA (Kanchanpur) and INF (Kaski) had recently employed new staff who had not received the refresher training as they did not meet the criteria for refresher training i.e. completion of six months since the basic training. Some IA trained CHBC teams also said that they needed more knowledge and skills for caring for children living with HIV.

### **Program planning and approach**

All the IA program plans and approaches were in line with the CHBC guidelines and SOPs. At the request of clients, the CHBC team provided services to PLHIV and their family members and maintained confidentiality. HIV care needs for clients were assessed regularly and the CHBC service maps were updated regularly.

All IAs were providing services to PLHIV clients in clearly defined geographic areas and limited to the program district. In one instance the CHBC program was serving clients living beyond their assigned geographical area. CHBC services were linked to ART and PMTCT sites and other needed services and had successfully mobilized community support for strengthening the CHBC program in their work areas.

### **Management and administration**

Most IAs had a system in place to cross-train staff/volunteers to ensure CHBC team members could be backed-up and replaced efficiently and were keeping all relevant documents related to the program according to ASHA Project requirements. All guidelines and documents were reviewed regularly. There was a designated CHBC supervisor at all sites and the supervisor routinely observed and mentored CHBC teams using supervision checklists and provided feedback to staff on their performance. Standard operating procedures (SOPs) detailing how the CHBC services are to be implemented were accessible to all relevant staff and both the management and program staff had been trained in the SOP requirements and use. Staff and volunteers reported that they were receiving ongoing mentoring, encouragement and supportive supervision from their supervisors and team members. Program reports, including service coverage indicators, were filed and readily available for review. All IAs have set targets for key performance indicators e.g., number of people receiving services, and performance against targets were reviewed by managers and staff on a regular basis. Most of the IA CHBC teams who are engaged in exposure prone procedures had received hepatitis B vaccinations and all selected IAs had access to nearby PEP, HIV care and ART services as well as care related to occupational exposure to HIV, which were provided free of charge.

## **General operational issues**

All CHBC programs had an office base with the basic facilities required to operate the CHBC activities. All CHBC sites had established essential referral relationships with an HIV care and treatment outpatient clinic, TB services, inpatient care and other services such as sexual and reproductive health (SRH) / Family Planning (FP), income-generation, and schools. All IAs were found referring clients to hospitals, IHS sites, care homes and other service sites for health related services and had a service referral directory, which was updated on a regular basis. The CHBC staff members communicated with referral sites and teams through various means such as phone, email and internet access. The CHBC teams did regular coordination and meeting with their respective outpatient clinic/hospital to improve and maintain the quality follow-up and referrals of the clients.

## **Infection control practices**

Most of the IAs were maintaining good infection control practices at the time of the study and were coordinating with other organizations, mainly hospitals and ASHA Project clinics for sterilization of equipment and waste disposal.

## **CHBC records and client registration**

All the CHBC programs visited had been maintaining standard ASHA project approved client registration and filing system and maintained confidentiality. There was evidence that CHBC teams promptly and completely fill in 'client first visit' and 'follow-up visit' forms. They recorded and maintained individual client files and maintained a system for managing active and inactive files for clients who were currently receiving services, for those who had died and those lost to follow up or discharged from the service. They were using the ASHA Project unique ID for each client to maintain confidentiality.

## **CHBC supplies**

Overall the CHBC supplies were maintained as per National CHBC guidelines. All teams had home care kits carried in a bag. The CHBC supplies were stored in a dedicated safe place and were replenished as required. All CHBC teams are trained to use the medicines and supplies in the kit. Some of the supplies, which were supposed to be with the CHBC teams, as per the guideline, were missing from the kit bags of some CHBC teams.

## **Home-based care visits**

### ***i) General home visit planning***

All IAs had maintained proper home visit plans. They provided clients with the required information on the CHBC service, its limitation before enrolling them in the CHBC program and maintained continuous communication and follow up with clients to ensure continuity of care to ensure that clients were not neglected. They also made sure that effective scheduling was in place for attending to clients. In most cases the IAs were prioritizing clients based on need and according to the SOP. They all had home visit plans and scheduled

home visits accordingly so that their clients were visited on a need basis: either daily, weekly, monthly or quarterly.

**ii) Home visit observation**

All IAs were well prepared and brought most of the supplies according to patient needs and home visit requirements. They appeared to have good working relationships with family members and stakeholders. During the home visits, CHBC service providers started the visit by inquiring about the needs of the PLHA and family, and following up on previously identified needs. They also conducted holistic assessments to learn more about the physical, emotional, social and spiritual needs of their clients. In two instances, CHBC teams had not informed their client before conducting the home visit. All IAs, apart from one, were implementing family-centered care i.e. addressed needs of the whole family, not just the individual with HIV, as required by the program.

**a) Physical care and support**

From the observations, all the IA CHBC teams were providing physical care and the support required. They carried out proper examinations of the clients as per guidelines and their training. During the visit, CHBC teams assessed and checked the previous clinic visit record and suggestions made, noted date of next visit, status of ART adherence and current problems experienced by the clients. They were observed to promote self-care skills and self-reliance of clients by using the different educational tools. They were also observed to be helping clients with pain management and have been providing information on safer sex, family planning, PMTCT, and harm reduction, as needed.

**b) Emotional, social and spiritual support**

IAs were found to be assessing clients and their families' emotional, social and spiritual needs. They were helping them to prepare a social, emotional, spiritual support plan and were arranging for follow-up counseling for both clients and families as needed. Most IAs were found to be referring PLHIV clients and family members to PLHIV support groups.

**c) Care for an HIV Positive and HIV-exposed/unknown status children**

All the IA were providing linkages and referral care to children and had CHBC kits containing supplies appropriate for children. Most IAs were found to be assisting in the proper care for children infected and affected by HIV by providing them with necessary information and referral services. In certain cases, referrals were made to link children with national level nutrition supplies/services e.g., de-worming, supplemental feeding etc. CHBC teams were providing information on HIV testing for infants and support in accessing HIV counseling and testing, if the family chooses. In the case of danger signs they referred the HIV positive child to the service site. In a few instances, CHBC members were found not firmly informing clients on the importance of exclusive breast feeding. Need assessments of children and providing relevant care and support did not appear to be well followed up. CHBC team members were found to have limited skills for caring for infected and affected children.

## **Community Services**

All IAs were observed to be regularly organizing community awareness activities to contribute to changes in knowledge among community members. They were involving the community to encourage a sense of ownership of the CHBC program; Conducted Stigma and discrimination reduction trainings; meetings with stakeholders involving the community members to address the barriers to PLHIV accessing care and support services. All the IA CHBC teams provided CHBC services to the client at home and community level e.g., drop-in centers, shelters, hospice care and crisis center settings according to the requirements and availability in the district. Naulo Ghumti's reporting in Kaski district showed that they did not have any clients wanting services in the community setting within their work area now and thus provided CHBC services at the home only.

## **Monitoring and evaluation**

All the IA CHBC coordinators were regularly monitoring the CHBC team members to ensure client satisfaction as well as confidentiality. Clients felt that they were being treated with respect and dignity by CHBC teams and that the CHBC teams carried out home visits for support at regular frequency and they were satisfied with the referral services. All the IAs had proper data collection forms and files and were found to be using those correctly. They were reporting on a monthly basis to ASHA Project and had a process in place for routine and participatory team analysis of program data. All IAs held quarterly review meetings (QRMs) to review and analyze target versus achievement. However in some IAs, CHBC teams appeared to have limited involvement in, or were leading the data analysis of findings to improve the program. Although all IAs were practicing QRMs, few IAs specifically mentioned the QRM activities during the QA/QI checklist review. However, some CHBC teams stressed the practice of target versus achievement analysis and organizing quarterly meetings to assess program efficacy and for making improvements.

### ***Part 2: Qualitative findings from 13 sites in selected districts:***

Qualitative data was extrapolated from in-depth group interviews with Program Managers (PMs) and Key Informants (KIs) comprised of HIV clinic manager, DACC member and PLHIV support group members in all 13 program districts. In addition, focus group discussions (FGDs) were conducted separately among CHBC clients and caregivers/family member of CHBC clients in three of the program districts (Doti –hill, Lalitpur – urban and Sunsari – terai).

The instruments that were developed for these activities were used in gathering data. The results were extrapolated using both software and recordings from the field. They were then scrutinized and were put in table format for reporting. The tables are representative of interactions with the above target groups in those districts

## **Summary of Qualitative Findings**

Four study population groups were interviewed as part of the qualitative study looking into CHBC access, quality of services and perceptions of CHBC in the community. Program managers represented service provider organizations in the districts; Key informants were

selected from government agencies and other individuals working closely with PLHIV communities, the caregivers (CHBC members) as well as the CHBC service receivers (PLHIV clients and their family members/caregivers) were interviewed using an interview and FGD guideline. Detailed responses received by each group in each site are available in Annex 2. To provide an overall perspective of the CHBC program being implemented in the 13 sites used for this study, a summary of qualitative findings is presented below.

The 13 sites assessed for CHBC services represented all three geographical and epidemic profile of the country (urban, hill and Terai). The types of responses from caretakers, caregivers, key informants or program managers were similar across geographical regions. The responses were similar regarding everything from their knowledge to the limitations of the program. There were no substantial differences in their perceptions of CHBC or associated programs for the PLHIV community. This similarity is attributed to the uniformity of the CHBC services being provided by ASHA Project in Nepal.

### **1. CHBC Program Managers/ Service Providers and Key Informants**

The CHBC Program Managers/service providers and Key informants were interviewed from each of the IAs and program districts to get their perspective on the following key areas:

- a. Understanding of the CHBC program
- b. QoL, emotional and social wellbeing of the PLHIV being served
- c. Activities under CHBC program and whether they meet the needs of the PLHIV being served
- d. Stigma and discrimination against PLHIV from community and family
- e. Government support

Qualitative information generated from interviews on each of these issues is summarized below:

#### **a. Understanding of CHBC program:**

*Overall response: Very important for the well-being of PLHIV*

When asked about their understanding of CHBC and the impact it had in the PLHIV community, most of them knew about CHBC, whom it targets and which organizations were running these services in their district. The services provided and the linkages with CHBC programs in each district sites were clearly understood by both service providers (SPs) and key informants (KIs). There was no doubt about their perception of CHBC and its usefulness in the community. CHBC programs were looking after the physical, mental and emotional well-being of PLHIV clients. Availability of CHBC program leads to increase in the quality of life of PLHIV and their family members. They all said that this was a very important program for the PLHIV community. Both groups (PM/SP and KIs) who were interviewed in all sites felt that CHBC programs were there for the wellbeing of PLHIV community. They all shared a similar opinion that without CHBC programs in place, the various services that were either directly or indirectly availed by the PLHIV clients would no longer be there and thus would be a loss to the community. CHBC was seen as being used by a large number of clients



through various NGOs working with PLHIVs. Key informants mentioned that PLHIV feel they can live as other normal people these days due to the support from services such as CHBC.

The program manager of Junkiri, in Banke district stated that PLHIV who previously didn't opt for CHBC services are now coming forward.

*Challenges: Limited Human Resources*

Common feedback was that CHBC services are not being reached by all the PLHIVs in need and this needs to be addressed. This appeared to be a consistent request from all sectors, from Doti/Kailali in the west to Sunsari in the East. Even Kathmandu respondents felt that the services weren't accessible to all PLHIV because the population of PLHIV in Kathmandu and Lalitpur districts is scattered. In the hills the lack of access appeared to be due to the geographical terrain and difficulties in reaching all VDCs within the district. The financial and human resource constraints were keeping the CHBC program from running more efficiently. Along with the above mentioned points, nutrition support, caring for children, Care Home facilities for those clients coming from long distances, transportation and treatment cost support for CHBC clients were all suggested by the respondents.

**b. Quality of life, emotional and social wellbeing of PLHIV being served**

*Overall Responses: Improved quality of life and emotional and social wellbeing*

Every program manager and key informant interviewed was of the opinion that quality of life (QoL) amongst clients had increased with the implementation of CHBC. They all understood that QoL ultimately led to the client leading a happy life, whether in terms of general health or self-esteem. They felt that emotionally and in terms of QoL, the PLHIV were doing better than before. The availability of counseling by peers, the option to choose to be independent, the availability of ART and being able to prolong their life, and the option of having someone to help when in need are some of the key reasons they felt that QoL among PLHIV clients has improved. Furthermore, they felt the emotional and social development of the clients has been positively influenced by their heightened feelings of self-esteem and self-confidence. Key informants mentioned that the social and emotional wellbeing are issues that once were major problems but are not so now due to this program and because of the involvement of government and various other organizations.

The key informants from Kapilvastu stated that the deaths in the district amongst PLHIV had started to go down as a result of CHBC services, as people had become more aware due to having increased access to health services and support groups.

A Key Informant from Surkhet felt that CHBC has played a major role in raising the QoL of PLHIV because the CHBC team is in regular contact with them and is providing HIV counseling to their families as well.

### *Challenges: Livelihood and new opportunities for income generation*

There was unanimous feedback that the livelihood/income generation improvement programs that the CHBC programs provide linkages to should be improved. For example, some existing programs have been continuing for a long period of time and were no longer seen as very helpful as livelihood options. Some program managers suggested providing income generating programs as part of CHBC rather than just linking with other organizations. Program managers and service providers of SAC felt that unless more income generating programs were devised, the QoL would not sufficiently improve. Apart from income generation activities, suggestions for investment in education, enhancement of skills of health personnel for treating PLHIV clients, more programs for community awareness, and skill developing trainings for single women were suggested as a means of increasing the QoL of PLHIV. KIs requested more innovative programs that would provide improved opportunities for income generation. Some KIs said that PLHIVs came for clinical services only after their CD4 count had gone down and when they were on medication due to secondary infections. They expressed their concern that clients should come for CHBC as well as other clinical services earlier, before their condition worsened. They also said that sustainability should be a focus of the program.

A key informant from Kanchanpur said that the PLHIV are facing problems in managing their basic needs due to poverty and the wives of the migrant workers are facing many problems.

### **c. Activities under CHBC program and whether they meet the needs of the PLHIV being served**

*Overall Responses: Noticeable improvements in lifestyle and emotional stability; need to link with different organizations to address the needs of clients*

In general, the activities provided under the CHBC program were found to be very important to the PLHIV community in all districts assessed. The program managers/ service providers and key informants felt that there were major improvements in the lifestyle and emotional stability of the clients due to the CHBC program and they expressed their appreciation. They said that the CHBC program looks after the physical, mental and emotional well-being of PLHIV clients along with other services as part of the program. The CHBC program links with different organizations to address the broader needs of clients. Most of the program managers said that the CHBC program has helped the community in terms of psychosocial support, health education, ART adherence, S&D reduction, linkages with different income generation programs, nutritional support and hygiene awareness. Some program managers mentioned that due to CHBC, PLHIV are also getting support from the district and village development committees and from the municipalities as well. Care Homes were very well received by PLHIV and were highly recommended. Many of these programs linked to or implemented through CHBC programs were carried out with support from ASHA project. Key informants said that due to CHBC, PLHIV feel that they can live as other normal people. CHBC programs provided services such as door to door services and client referral and also helped to minimize discrimination and ensure regular intake of their ART medication.

The KIs from Kapilavastu said that deaths due to HIV had started to go down as a result of CHBC services because people were becoming more aware due to increased access to health services and support groups.

*Challenges: Clients reached at a late stage*

There were widespread concerns that the self-sustaining activities needed to be broadened in CHBC. The CHBC program should provide income generating activities as part of CHBC rather than just linking with other income generating programs. There was also a concern that clients normally came to them in the later stage of HIV because they are sick and this bothered them immensely. They requested that more awareness activities be done so that clients would be informed and referred to them earlier. There were also concerns that Care Homes were very important for ART initiation and monitoring of ART adherence and side-effects although they are not part of the CHBC programs. Key informants from BIJAM in Parsa heightened the importance of strengthening CHBC and ART networking. Many of the groups interviewed felt that the CHBC support might end due to program funding limitations. The program manager of Youth Vision suggested that different modalities of CHBC should be made available for urban and rural communities.

**d. Stigma and Discrimination against PLHIV by family and community:**

*Overall Responses: The CHBC program improved awareness and understanding on HIV through relationships and dialogue with the wider community*

Stigma and discrimination (S&D) was an issue that the program managers and service providers felt was improving with time in their community. They were of the opinion that the CHBC team did a good job of reducing the S&D towards the PLHIV, however, S&D was still existed, although with less frequency. They said that children were also victims of HIV related S&D. Key informants said that the attitude and thinking of the PLHIV has also changed. For example, they used to even contemplate suicide due to low self-esteem and discrimination but today the situation is different. They felt that now the PLHIV clients have become much more aware and are working for the benefit of the PLHIV community as a whole. CHBC teams have provided the PLHIV with the added self-confidence to seek support on S&D issues within the family and the community. Furthermore, CHBC support ensured that these clients no longer had to resort to reclusive behavior as the fear of being stigmatized and discriminated against is less.

*Challenges: Stigma and discrimination is still the challenge*

In spite of the efforts to reduce S&D and the general perception that it is reducing in the CHBC program areas, it still persists. According to those interviewed, the S&D although reduced, is still apparent in the community and is one of the biggest challenges of the CHBC program. In the rural communities the respondents felt that the upper class families displayed the most S&D against PLHIV, while in the urban settings it was felt most from the more educated people. Program managers said that S&D even existed in hospitals, and in some cases, the patients with HIV were not treated as equals with other patients. Regardless, S&D still plays a big role in the lives of PLHIV in terms of leading a normal life.

The suggestions provided by the interviewees included community awareness programs such as street plays, radio programs, and board messages; making HIV awareness part of the school curriculum; training community volunteers to better to share positive messages in the community.

A key informant from Kaski said that there is still misunderstanding about HIV. For example, people still discriminate people living with HIV by not touching them, not visiting them or not eating with them etc.

#### **e. National Ownership**

*Overall responses: Satisfactory national support for CHBC*

The CHBC program continues to run under the leadership of Government of Nepal and the support of I/NGOs working in the area of HIV/STI in the country. The respondents were satisfied with the general level of support and there were no major issues. They felt that the current national support to ASHA Project as well as CHBC programs run by different INGOs in Nepal was satisfactory. The role of the DACC coordinator was seen as positive by the KIs. KIs from Banke also said that they were happy that NCASC has provided 15 different types of HIV related tests free of cost at ART clinics, which has certainly helped the PLHIV community.

*Challenges: National role in CHBC*

When probed deeper, program managers and key informants suggested that increased national ownership would in turn increase the coverage of CHBC and reach more PLHIV. Key informants emphasized that CHBC should get the same status as the TB program in the country. KIs also emphasized the importance of strengthening the networking between DACC, NCASC and NGOs. At the same time, they felt that funding for CHBC should be increased to help train more personnel and volunteers to reach out to the community.

A key informant from Kailali said that more national program support is required, for things such as nutritious food for children, and provision of employment and economic enhancement opportunities.

A key informant from Kapilvastu said that it is important to build national ownership to include CHBC, along with other relevant programs in the health system. Another respondent from Kaski suggested something similar to the National Tuberculosis Program.

## **2. Care Takers/Receiver and Caregivers**

The information gathered from caregivers and caretakers was limited due to their reluctance to engage in long conversations with the research team. Often during FGDs, only those with a close connection to the CHBC team responded to the questions. The ones who did respond to queries and joined in the discussions were forthright and to the point, thus the information gathered clearly describes the benefits and challenges faced by these groups with regard to CHBC.

### *Overall findings: Continuation of CHBC is important*

The caretakers and caregivers in all districts requested the continuation of this program. They were worried about possible limitations to the services provided due to funding cuts to the program. The caretakers of PLHIV clients that were interviewed in the three purposively selected sites (Doti, Lalitpur and Sunsari) were all satisfied with CHBC services and the quality of services provided. The common response was that the CHBC program was very beneficial in terms of the positive change in their quality of life, overall health and related support mechanisms (social support, ART medication support etc.). The support received from the CHBC team helped PLHIV clients to disclose their HIV status. They felt that the services could be improved by increasing the number of CHBC teams and the frequency of home visits, when required. They thought that the community should be more aware of PLHIV issues with involvement of the CHBC team.

The caregivers were all very aware of the services being provided through the CHBC program and had a clear understanding of the difficulties faced by the PLHIV clients.

The following are excerpts from CHBC clients describing the benefits of CHBC:

A CHBC service receiver from Sunsari said that the CHBC team has taught many things, for example, how to make *sarwottam pitho* [flour based supplement], mixing the beans and making *sattu* [nutrition supplement]. “They [CHBC team] talk to us like normal people. They tell us useful things and take good care of us. They answer us properly if we ask them anything. They listen to us properly which makes us relaxed. When they do this, we feel like we have someone who understands.”

Another CHBC client from Lalitpur said “The CHBC team takes very ill clients to the hospital for treatment. CHBC serves the clients at home if they are unable to take care of themselves. This is very helpful.”

### *Challenges: S&D reduction*

There was a sense that PLHIV clients and caregivers were trying hard to reduce S&D in the community, and at times they too felt stigmatized. They felt that S&D has reduced somewhat but that it still exists in the community. They also felt that a lot was expected of them by the PLHIV community. The caregivers and care providers were concerned about continuity of the CHBC program in their districts. They were of the opinion that human resources needed to be increased, and if not, this would lead to difficulties in providing support to all clients who need services. They suggested increasing human resources as well as support in terms of transportation required to reach the clients.

### **IV.3 Objective 3: To measure the physical and psychosocial wellbeing of and differences between CHBC clients and non-CHBC clients.**

The CHBC and control (non-CHBC) district comparison approach used for this objective has several limitations and assumptions. The study populations being compared are only those PLHIV (above 18 years of age) who were on ART. Firstly, this is an assessment of only 44

percent of the PLHIV clients being served through the CHBC programs because the other 66 percent of the clients are not on ART. Secondly, CHBC service is an optional service and service intake is based on the PLHIV client decision. Thirdly, the three control districts (non-CHBC districts) selected to represent each of the geographical criteria meant that these control districts were assumed to be representative of all non-CHBC districts. Lastly, although the PLHIV study populations in both arms were matched on their ART status, the differences between the PLHIV on ART and those not on ART in the control districts are not known. In other words, there may be some PLHIV in the control districts who were not on ART but should have been on ART and hence, there may be sampling bias in the type of controls selected. Considering all these limitations, the bivariate and regression analysis findings on the primary and secondary outcomes are as follows:

## **BIVARIATE ANALAYSIS**

### ***Primary outcome: physical and psychosocial symptoms:***

The index variables were created grouping the key symptoms and weighing them by level of perceived severity. The indicators were created as a binary variable by setting a cutoff value based on the level of severity.

All 25 queries for psychosocial symptoms (measuring emotional wellbeing) as per Memorial Symptom Assessment Scale (MSAS) (Section 4, Annex 3.1) were assessed for analysis. Weightage values were calculated using 2 (little), 3 (quite a bit) and 4 (Extreme) as base value. The base value of 1 (no pain) was not taken. The cut off value for the analysis was calculated to be less or equal to 14 for less severe (up to third quartile) and more than 14 for very perceived severe psychosocial symptom.

For physical pain symptoms Memorial Symptom Assessment Scale (MSAS) (Section 3, Annex 3.1) was also used for analysis. A total of 14 pain indicators were chosen from among 30 available indicators. Those were: Lack of energy, Nausea, Vomiting, Feeling drowsy, Diarrhea, Problems with sexual interest or activity, Itching, Lack of appetite, Dizziness, Vaginal or penile discharge, Pain, Numbness/shooting pain/tingling in hands/feet, Difficulty swallowing; painful swallowing, Painful skin rash. Severity of pain variable was chosen for weightage value calculation. This parameter had four possible outcomes- slight, moderate, server and very severe. The cut off value for the analysis was calculated to be less or equal to 10 for less Severe (up to third quartile) and 11 and above for Severe pain.

Results showed that generally less clients reported perceived severe psychosocial or physical symptoms. Overall, the control group had more instances (71% vs 67%) of 'Not Severe' cases in terms of psychosocial symptoms (Table 5). A similar finding was also observed for 'Not Severe' physical pain (83% vs 64%) (Table 6). The values, when calculated for significance returned significant values ( $p < 0.05$ ) for psychosocial pain suggesting controls were less likely to have severe pain than the CHBC group. Also, the test for significance showed a highly significant difference ( $p < 0.001$ ) in terms of severity suggesting controls were less likely to have severe cases of physical pain compared to their CHBC counterparts.

Table 5. Comparison of weighted perceived psychosocial symptoms (severity index) variables grouped together for control and CHBC groups.

Overall Pain	CONTROL (%) N=140	CHBC (%) N=140	P- Value
Not Severe	111 (71)	94 (67)	0.03*
Severe	29( 21)	46 (33)	

\*significant

Table 6. Comparison of weighed perceived physical pain symptoms (severity index) between control and CHBC groups.

Overall Pain	CONTROL (%) N=140	CHBC (%) N=140	P- Value
Not Severe	116 (83)	89 (64)	<0.001**
Severe	24( 17)	51 (37)	

\*\* highly significant

## Secondary Outcomes:

### *I. Quality of Life (QoL) indicators:*

The QoL assessment carried out as per WHO selected four domains suggests no apparent difference between the two groups. This physical health domain (Domain 1) incorporated the following facets: dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest as well as work capacity. The Psychological domain (Domain 2) incorporated the following facets: bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality/religion/personal beliefs, thinking, learning, memory and concentration. The social relationship domain (Domain 3) incorporated factors representing personal relationships, social support and sexual activity. The Environment domains incorporated factors representing financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment (pollution/noise/traffic/climate), and transport. The differences in mean values for the four domains were not significantly different, suggesting that in terms of the domain scores, the overall perceptions of clients in both groups towards their QoL were similar. When comparing the means of the domain scores (Table 7 and 8), the mean score is slightly higher for the CHBC group than control group for all four domains.

Table 7. Descriptive statistics of the four domain scores for control group

CONTROL GROUP: Descriptive Statistics					
	N	Min	Max	Mean	SD
Domain 1: Physical health	140	8.00	17.14	12.84	1.42
Domain 2: Psychological	140	8.67	18.00	12.65	1.84
Domain 3: Social relationships	140	5.33	20.00	13.84	2.68
Domain 4: Environment	140	6.00	18.00	12.53	2.20

Table 8. Descriptive statistics of the four domain scores for CHBC group

CHBC GROUP: Descriptive Statistics					
	N	Min	Max	Mean	SD
Domain 1: Physical health	140	6.86	17.14	12.86	1.54
Domain 2: Psychological	140	6.67	18.00	12.81	2.11
Domain 3: Social relationships	137	8.00	20.00	14.03	2.70
Domain 4: Environment	140	7.50	19.50	13.15	2.04

## II. Health indicators:

### a. ART Adherence

The ART adherence based on one week recall by clients was very high for both groups and not significantly different (Table 9). Similarly, instances of missing medication in a 48-hour period was low in both groups (Table 10) but significantly higher for the CHBC clients than control by almost eight percentage points. This shows that the PLHIV community is aware of the benefits of timely ARV treatment, whether they are on CHBC or not. The ART medication adherence measured for the month prior to the interview, showed that the control group adhered to their regimen more than the CHBC group (insignificant) (Table 11). All three indicators show that at the bivariate level, the CHBC group had lower ART adherence than the control PLHIV group.

Table 9. Comparison of ART adherence in the last one week as reported by clients

Medication during last week	Control (%) (n=140)	CHBC (%) (n=140)	p-value
did not forget	135 (96.4)	129 (92.1)	0.255
forgot once or more	5 (3.6)	9 (3.6)	
Not Sure	0 (0)	2(0.7)	

Table 10. Comparison of instances of stopping of ART medication during 48 hour regime between two groups

Stopped taking ART for more than 48 hours	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	4(2.9)	15(10.7)	<0.01**
No	136(97.1)	124(88.6)	
No Answer	0(0)	1(0.7)	

\*\*highly significant



Table 11. Comparison on intake of ART medication in the last month between two groups

how much of prescribed ART taken last month	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Not all	8 (5.70)	19 (13.5)	0.21
All	132(94.3)	121(86.4)	

Similarly, side effects were reported by both groups of clients on ART. Loss of appetite and nausea, which are normally interlinked, were found to be the major side effects associated with ART regimen in both groups. In both the CHBC and control groups, around 70 percent reported experiencing any side-effects in the first three months of undergoing treatment (Table 12). On the other hand, the reports of experiencing any size effects from ART in the past month was much lower for both the CHBC and control groups at around 17 percent, with no significant difference between the two groups (Table 13).

Table 12. Comparison between two groups regarding presence or absence of side effects to ARV treatment in the first three months of undergoing treatment

Side Effect of ART	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	97(69.3)	98(70)	0.57
No	43(30.7)	41(29.3)	
Don't Know	0(0)	1(0.7)	

Table 13. Comparison between the two groups regarding Client responses regarding presence or absence of side effects to ARV treatment in the past month

Side Effect of ART	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	25 (17.9)	24 (17.4)	0.37
No	113 (80.7)	114 (82.6)	
Don't Know	2(1.4)	1(0.7)	

#### **b. Health Seeking Behavior of PLHIV**

Clients in both groups were found to seek help for their condition. This is clearly reflected in Table 14, where the majority reported that they had never missed a medical appointment but the proportion missing medical appointments was higher among CHBC clients although not significant at the 0.05 level. This shows that the PLHIV in the control group were similarly or slightly more conscious of their health.

Table 14. Comparison between two groups regarding whether they missed medical appointment related to HIV in the last one year

Missed HIV appointment last year	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	5(3.6)	13(9.3)	0.05*
No	135(96.4)	125(89.3)	
No Answer	0(0)	2(1.4)	

\*significant

As illustrated in Table 15, while the CHBC clients reported receiving care mostly from the CHBC services, the majority of the control district PLHIV were found to either provide self-care or visit the district hospital. This is an important finding, indicating the importance of CHBC services to clients diagnosed with HIV and the uptake of CHBC services where they are available.

Table 15. Comparison between the two groups regarding their response on the place where they went to received care for their physical symptoms.

Who provided care (n=140)	Control (%) (N=140)	CHBC (%) (N=140)
ART center	11 (7.9)	19(13.6)
CHBC team	0	54(38.6)
PLHIV group/peer	12(8.6)	12(8.6)
Family	6(4.3)	17(12.1)
Self	25(17.9)	14(10)
District Hospital	22(15.7)	15(10.7)
Private clinic	16(11.4)	14(10)
Others	20(14.3)	17(12.1)

### c. Perception of Health:

There were significantly higher percentages of clients with low self-reported latest CD count (<350 per ml) in the control group than in the CHBC group (Table 16).

Table 16 . Current Self-reported latest CD4 count (per ml blood) as reported by two groups

CD4 count/ml (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	P value
350 or less	95(67.9)	70(50)	<0.01**
351 or more	45(32.1)	70(50)	

\*\*highly significant

The comparison of self-reported weight of clients between CHBC and control groups showed that there were significant correlations between the two groups (Table 17). Interestingly, the lower weight was prominent in the CHBC group while the control had a higher proportion of higher weight (>60 kg).

Table 17. Current self-reported weight (in kilograms) as reported by the two groups

Current weight (in kilograms)	Control (%) (N=140)	CHBC (%) (N=140)	P value
40 or less	8(5.7)	20(14.3)	0.02
41-50	53(37.9)	56(40)	
51-60	47(33.6)	50(35.7)	
61 or more	22(15.7)	12(8.6)	
Did not know	10(7.1)	2(1.4)	

\*\*highly significant

The PLHIV on ART were generally satisfied with their current health, as shown in the Table 18, regardless of CHBC services. Only about 13 percent of the PLHIV in the control group and 8 percent in the CHBC group reported falling ill regularly in the past month. The majority reported not falling ill in the past month with this being slightly higher for CHBC group.

Table 18. Comparison of the frequency of reported illness in the past month between the two groups

Ill health past month (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p- value
Regularly in the month	18(12.8)	11(7.8)	0.28
once or twice in the month	32(22.9)	29(20.7)	
no ill health	90(64.3)	100(71.4)	

Level of satisfaction with current health appeared to be similar across the groups as there was no significant difference in the results (Table 19). This may be due to the fact that both groups consisted of PLHIV on ART and so the current health may be similar because of the ART.

Table 19. Level of Satisfaction of clients with current health between the two groups

Health Satisfaction (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p- value
Dissatisfied	10(7.1)	9(6.4)	0.07*
Indifferent	38(27.1)	46(32.9)	
Satisfied	92(65.7)	85(60.7)	

\*significant

Furthermore, a higher number of PLHIV in the control group reported that they required high level of medical treatment per day as compared to those in the CHBC group (69% vs 56% respectively).

Table 20. Comparison of the frequency of medical treatment required on their daily lives between the two groups

Need Medical treatment required in daily life (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	P value
Low	21(15)	34(24.3)	0.08=7
Medium	23(16.4)	28(20)	
High	96(68.6)	78(55.7)	

\*\*highly significant

#### d. HIV related deaths in family

A third of the respondents in both groups reported losing a family member to HIV but there was no difference in the response between the two groups (Table 21). This indicates that regardless of whether CHBC services are provided or not, there was a likelihood that a family member of a current PLHIV member had passed away at some point from HIV infection. Among those who reported deaths from HIV in the household, the majority had one death case (not shown).

Table 21. Comparison on the HIV related deaths in families in two groups

Family member HIV death (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	P value
Yes	47 (33.6)	52(37.1)	0.37
No	93 (66.4)	88(62.9)	

### III. Psycho-social

#### a. perceived material and inter-relational social support

Table 22, shows that a significantly higher proportion of CHBC clients had someone to talk to about their problems as much as they liked. This social support appears to be significantly lower for the PLHIV in the control districts than that in the CHBC districts. The opportunity to talk with CHBC service providers during their home visits to the PLHIV may be one reason for a higher proportion seen in the CHBC district. Table 22 further supports this by showing that CHBC clients were more likely to talk to PLHIV support group members, CHBC/ART staff and counselors when they were feeling low.

Table 22. The perceptions of clients regarding the opportunity to talk to someone regarding their problems or worries

Get chance to talk to someone about your problems (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
As much as I would like	66 (47.1)	87 (62.1)	0.02*
Less and much less than I would like	56 (40.0)	34(24.3)	
Never	18 (12.8)	19 (13.5)	

\* significant

Table 23. Response regarding what clients did when they were feeling low

When feeling low what you do	Control (%)	CHBC (%)
Talk with family	68	55
Talk with friends	79	74
Go to PLHIV support group meetings	5	14
Talk with CHBC/ART staff	3	26
Seek counseling from CHBC/ART staff	6	18
Take medicine	9	3
Work	41	21
Sleep	23	12
Try to distract myself	18	36
Drink	1	3
Take drugs	1	2
Watch TV	39	49
Nothing	0	5
Other joking with friends, playing with children	49	44

# multiple response question and so total may exceed 100%

In terms of the receiving enough support from friends and family, around 50 percent in both groups reported getting the support they would like (Table 24). A higher proportion of the CHBC clients reported never receiving enough support from their family and friends. This may indicate higher expectations by the clients in CHBC service or that families and friends may not be fully sensitized to the need for continuous support.

Table 24. Perceived support from friends and family between the two groups

Support from friends and family	Control (%) (N=140)	CHBC (%) (N=140)	p-value
as much as I would like	70 (50)	73 (52.1)	0.25
Less and much less than I would like	60 (42.9)	50 (35.7)	
Never	10 (7.10)	17(12.1)	

When comparing the PLHIV respondents' perceptions on the love and affection they received from the people they care about, the CHBC PLHIV group reported receiving as much love and affection as they would like but also had a higher proportion reporting never receiving love and affection (Table 25).

Table 25. Perception of love and affection from people close to them between the two groups

Get love and affection from people you care about	Control (%) (N=140)	CHBC (%) (N=140)	p-value
As much as I would like	98 (70)	112(80)	<0.01*
Less and more less than I would like	38 (27.1)	18(12.9)	
Never	4(2.8)	10(7.10)	

\* significant

The majority of the PLHIV respondents in both groups reported getting help when they were sick. There was no significant difference between the two groups but a higher proportion of PLHIV respondents receiving CHBC services reported getting both as much help when sick and never getting help when sick (Table 26). More respondents in the control group as compared to CHBC group responded that they received less than expected access to support when sick.

Table 26. perceptions regarding access to help when sick between the two groups

Get help when sick(n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
As much as I would like	102(72.9)	107(76.4)	0.17
Less and much less than I would like	33(23.6)	23(16.4)	
Never	5 (3.5)	10(7.10)	

**b. Disclosure:**

There was a significant difference in keeping HIV status secret between PLHIV on ART in the CHBC group and control group (Table 27). The PLHIV respondents receiving CHBC services were twice as likely to generally disclose their HIV status compared to those in control group. This may indicate that exposure to CHBC services has increased the confidence among PLHIV to disclose their HIV status.

Table 27. Comparison of General disclosure regarding HIV status between two groups

Generally Keep HIV status secret (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	87 (62.1)	44(31.4)	<0.001**
No	53(37.9)	96(68.6)	

\*\*highly significant

**c. Agency**

**i. Perceived self-confidence**

The perception of self confidence amongst the respondents in terms of avoiding or isolating oneself from friends or family because of their HIV status was that majority (more than 80 percent) didn't isolate themselves and no significant difference was observed between the two groups (Table 28).

Table 28. Avoiding or isolating oneself from friends or family because of HIV status in the past year

Isolated self due to HIV status (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	18 (12.9)	26(18.6)	0.19
No	122 (87.1)	114 (81.4)	

Similarly, the majority of clients rated themselves as being highly self-confident scoring a 10 followed by a high proportion of medium high self-confidence (6-9 score). This shows that at present, clients were generally happy with their level of confidence. When comparing the two groups, there was no significant difference although, the CHBC group had a slightly higher proportion for the highest self-confidence, average and low confidence (Table 29).

Table 29. Comparison of the self-rated confidence level between the two groups

<i>Self- rating for confidence</i>	Control (%) (N=139)	CHBC (%) (N=137)	p-value
Low(1-4)	6 (4.3)	10 (7.3)	0.14**
Average(5)	8 (5.8)	14 (10.2)	
Medium high (6-9)	62(44.6)	45(32.8)	
High (10)	63 (45.3)	68 (49.6)	

\*\*highly significant

The majority of the clients felt that knowing their HIV status has not been good for them overall. The clients not on CHBC were significantly more likely to feel this way compared to those on CHBC (Table 30). This shows that the support provided by CHBC may have helped reduce the negative perceptions about knowing ones HIV positive status. However, the overall negative perception shows that more focused support is needed to overcome this concern.

Table 30. Perceptions of clients regarding whether having the knowledge of their HIV status was beneficial to them

Knowing HIV status good for you(n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	41(29.3)	52(37.1)	0.15
No	99(70.7)	88(62.9)	

## ii. Capacity to care for self

There were no significant differences between the two comparison groups in terms of their capacity to care for self. The general satisfaction with ability to carry out daily activities appeared to be similar in both groups. There was no major difference between the groups. Only about 10 percent of the study participants in both groups were dissatisfied with their ability to perform daily activities (Table 31). The overall satisfaction with self was also similar

between the two groups with less than nine percent reporting being dissatisfied with self and more than 60 percent reporting being satisfied with self (Table 32). This finding once again reflects the enhanced self-confidence perceived by the PLHIV community in Nepal.

Table 31. Satisfaction level with the ability to perform daily living activities by the two groups

Ability to perform daily living activities	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Dissatisfied	14 (10.0)	13 (9.3)	0.76
Indifferent	43(30.7)	47 (33.6)	
Satisfied	83(59.3)	80 (57.1)	

Table 32. Satisfaction with self as reported by the two groups

Satisfaction with self	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Dissatisfied	12 (8.6)	10 (7.1)	0.49
Indifferent	39 (27.9)	45 (32.1)	
Satisfied	89 (63.6)	85(60.7)	

#### d. Stigma and Discrimination (S&D):

The PLHIV community interviewed stated that they did not normally encounter feelings of stigma and discrimination in the last three months. Table 33, shows that the response was not significantly different between the control group and CHBC group (86% vs 87% respectively).

Table 33. Feeling of Stigma and Discrimination by clients during the last three months

Feeling of Discrimination (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	19 (13.6)	18 (12.9)	0.80
No	121 (86.4)	122(87.1)	

Among those who reported feeling stigmatized and discriminated against, the majority of the S&D was by other family members or neighbors (Table 34). Therefore it appears that S&D needs to be addressed in the communities where PLHIV live.



Table 34. Response from clients as to who they felt discriminated against them

Discriminated by	Control (%) (N=140)	CHBC (%) (N=140)
parents	0 (0.0)	4 (2.9)
other family	7(5)	8 (5.7)
neighbours	9 (6.4)	12 (8.6)
at work	3 (2.1)	1 (.7)
at market	4(2.9)	2 (1.4)
clinic staff	0 (0.0)	1 (.7)
hospital staff	0 (0.0)	1(.7)
CHBC team	0 (0.0)	1(.7)

#### IV. Prevention/behavioral

##### *Knowledge of safer sex practices*

Table 35 illustrates the respondent's knowledge on safer sex practices for HIV prevention mainly on the three key indicators: A - abstinence, B- Being monogamous, and C - correct and consistent condom use. More than 55 percent of PLHIV in both groups correctly answered that abstinence was one of the means of preventing HIV infection and no significant difference was observed between the two groups. Knowledge on indicator B (being monogamous) was significantly higher among the control PLHIV respondents than the CHBC group. Both groups had the highest knowledge on correct and consistent condom use for preventing HIV (above 93%). When comparing the knowledge on all three ABC indicators, the proportion was much lower in both groups (no significant difference between groups) and this was because of the low proportion on knowledge on abstinence.

Table 35. Comparison on knowledge on safer sex practices for prevention of HIV transmission between the two groups

	Control (%) (N=140)	CHBC(%) (N=140)	p-value
Can protect from HIV by <b>Abstaining</b> from sexual intercourse (A)	86 (61.4)	79 (56.4)	0.40
Can prevent HIV transmission by <b>Being Monogomous</b> with uninfected partner (B)	120(85.7)	104(74.3)	0.02*
<b>Condom</b> use imp for preventing HIV (C)	131 (93.6)	134 (95.7)	0.43
<b>Knowledge of ABC indicators</b>	77 (55)	67 (47.9)	0.23

\* significant

### ***Safer sex practices application***

Sexual intercourse had previously been experienced by majority of clients in both groups (data not shown). However, the number of current sexual partners as being zero was reported by about 30 percent of the clients in both groups in current context (Table 36). The majority of those interviewed reported having only one sexual partner (around 68% in control group and 56% in CHBC group). There was no significant difference between the two groups.

Table 36. Comparison of number of current sexual partners by the two groups

no. sexual partners	Control (%) (N=133)	CHBC (%) (N=134)	p-value
none	39 (29.3)	48.0(35.8)	0.05
one	91(68.4)	76.0(56.7)	
more than one	3.0(2.3)	10.0(7.5)	

About 55 percent of the CHBC clients and 60 percent of control group PLHIV reported having used condom during last sex with their regular partner (Table 37). Similarly the use of condom in regular sexual activity in the past one year was also high for both groups of clients (Table 38).

Table 37. Use of condom during last sex with regular partner by the two groups

Regular Sex Partner condom use recently (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
yes	85 (60.7)	77(55.0)	0.33
no	55 (39.3)	63(45)	

Among the PLHIV who had sexual intercourse in the past 12 months, (n= 90 for control and n= 86 for CHBC group), about 80 percent in both groups responded consistent condom use in the past year (Table 38). Very few (7% control and 4% CHBC) had never used condoms in the past one year. However, inconsistent condom use with their regular partners even after knowing their HIV status is seen in both groups, putting their sexual partner at risk.

Table 38. Consistent condom use by PLHIV with their most regular partner in the past one year

how often condom use in past one year	Control (%) N=90	CHBC (%) N=86	p-value
All of the time	72 (80)	69 (80.2)	0.81
Mostly, sometimes or rarely	11 (12.2)	13 (15.1)	
Never	7 (7.8)	4 (4.7)	

**Risk Behavior: Alcohol and Substance abuse**

Majority of the PLHIV in both groups (about 90 %) stated that they did not drink alcohol in the past month (Table 39). Only a very small proportion reported drinking at least once a week and there was no difference between the two groups.

Table 39. Frequency of alcohol usage in the past one month by two groups

Frequency of alcohol past month	Control (%) (N=140)	CHBC (%) (N=140)	p-value
never	130 (92.9)	124 (89.2)	0.54
less than once a week	6 (4.3)	8 (5.8)	
at least once a week	3 (2.1)	7 (5.0)	
Did not know	1 (0.7)	1 (0.7)	

Similarly, most of the clients reported that they had never injected drugs in their lives (Table 40) The proportion of PLHIV who had ever injected drugs was significantly higher among the CHBC clients. Among those who reported to have ever injected drugs, none of the injecting drug users from the control group and four out of the 28 (around 14%) from the CHBC group reported having injecting drugs in the past six months. Out of those four injecting drug users from the CHBC group, two reported injecting drugs in the week prior to the study (data not shown).

Table 40. Frequency of alcohol usage in the past one month by the two groups

Ever injected drugs	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Yes	5 (3.6)	28 (20.0)	<0.001**
No	135 (96.4)	112 (80.0)	

\*\*highly significant

Similarly, drug smoking habits in the past six months at a frequent level was observed to be significantly higher among the PLHIV in CHBC group than control group (Table 41).

Table 41. Frequency of smoking drugs last six months

Frequency of smoking drugs last six months (n=140)	Control (%) (N=140)	CHBC (%) (N=140)	p-value
Never	119 (85)	94 (67.10)	<0.001**
Rarely	4 (2.9)	4 (2.9)	
Frequently	17 (12.1)	42 (30.0)	

\*\*highly significant

## REGRESSION ANALYSIS

Regression analysis was carried out on key indicators based on findings of primary outcomes as a result of bivariate analysis. Logistic regression was conducted for the outcomes that were binary in nature and linear regression was conducted for continuous outcomes. While a large number of indicators were selected for the bivariate analysis, regression analysis was performed only for selected key variables found to show significant or close to significant difference in the bivariate analysis. The independent variable of interest was the intervention group (CHBC or Control) and various socio demographic variables, such as, age, gender, literacy, marital status and geographical region were adjusted for confounding in all the regression models. Results were taken as being significant if  $p < 0.05$  and highly significant if  $p < 0.001$ .

### **Primary outcome:**

#### **Overall physical and psychosocial symptoms :**

Logistic regression assessment using physical symptoms and psychosocial symptoms as dependent variable and CHBC group as independent variable in two separate regression models showed that there was significant positive association for physical symptoms only. The regression analysis shows that the CHBC group had significantly higher odds of suffering from perceived severe physical symptoms after adjusting for possible confounders. Although the CHBC group also had higher odds (adjusted OR=1.7) of suffering from perceived severe psychosocial symptoms than control group, it was not significantly higher as the 95% lower confidence interval had an OR of 1.0 (Table 42).

Table 42. Logistic regression analysis of overall perceived severe physical and psychosocial symptoms in relation to intervention group (CHBC group versus control) against selected confounders

	Perceived Severe physical symptoms	Perceived Severe psychosocial symptoms
	Adjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: control group)	3.8 (2.0-7.2)	1.7 (1.0-3.1)

† adjusted for age, gender, literacy, marital status and geographical region

### **Secondary Outcomes:**

#### **I. Quality of life**

The WHOQOL-BREF questions (abbreviated version of WHOQOL-100) was used to measure Quality of Life (QoL). Table 43 illustrates the results from the four separate multiple linear regression outputs of each of the QoL domains.

### Domain 1: Physical Health

This physical health domain incorporated the following facets: dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest as well as work capacity. Multiple linear regression model looked at the association between the physical health domain and intervention group (CHBC versus control group). There was no significant difference between the domain score of CHBC and Control group. The physical health QoL score is slightly better for the CHBC group by 0.23 after adjusting for possible confounders.

### Domain 2: Psychological

The Psychological domain incorporated the following facets: bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality / religion / personal beliefs, thinking, learning, memory and concentration. The regression shows that the CHBC group has a significant positive association with psychological domain score, meaning that the domain score is better for the CHBC group by 0.60 points compared to the control group after adjusting for possible confounders.

### Domain 3: Social relationships

This domain incorporated factors representing personal relationships, social support and sexual activity. There was no significant difference in the association between CHBC groups with social relationships domain score.

### Domain 4: Environment

This domains incorporated factors representing financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation / leisure activities, physical environment (pollution / noise / traffic / climate), and transport. The findings show that there is a significant positive association between CHBC group and the environment domain as the CHBC group showed an increase in domain score by 0.74 points compared to the control group after adjusting for possible confounders (Table 43).

Table 43. Multiple linear regression analysis of Quality of Life (QoL) indicators using WHO-defined domains

QoL Domains	Domain 1: Physical health		Domain 2: Psychological		Domain 3: Social relationships		Domain 4: Environment	
	B (95% CI)	P Value	B (95% CI)	P Value	B (95% CI)	P Value	B (95% CI)	P Value
CHBC group† (Ref: Control )	0.23 (-0.20,0.65)	.29	.60 * (0.11,-1.09)	.02*	0.38 (-0.21,0.97)	.20	0.74 (0.28-1.21)	<0.01*

† adjusted for age, gender, literacy, marital status and geographical region

\* Significant at 0.05 level

## II. Health

### a. ART adherence

The dependent variable used for the regression was complete ART adherence in the last week. After adjusting for potential confounders in the logistic regression model, there was an insignificant association between complete ART adherence and CHBC group. The CHBC group had lower odds of complete ART adherence compared to control group (OR=0.4) after adjusting for potential confounders (Table 44).

Table 44. Association of intervention group (CHBC group versus control group) with complete ART adherence (100%) in past week in multivariable logistic regression

	Complete ART adherence
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: control group)	0.4 (0.1-1.4)

† adjusted for age, gender, literacy, marital status and geographical region

### b. Health seeking behavior:

The dependent variable assessing health seeking behavior was never missed an HIV appointment in past year. As illustrated in Table 45, the adjusted OR value for CHBC group was 0.36 compared to control, meaning that CHBC group had 64% less odds of never missing HIV appointments (not significant).

Table 45. Association of intervention group (CHBC group versus control group) with health seeking behavior (never missed a HIV appointment in past year) in multivariable logistic regression

	Never missed a HIV appointment in past year
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: control group)	0.36 (0.116 – 1.122)

† adjusted for age, gender, literacy, marital status and geographical region

### c. Perception of health status

Frequency of illness in past month

The dependent variable of interest was not reporting illness in past month. CHBC group had higher odds of not suffering from illness in past month than control group (OR=1.36) although not significantly higher (Table 46).

Table 46. Association of intervention group (CHBC group versus control group) with sickness frequency in past month in multivariable logistic regression

	Frequency of illness (no illness)
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: control group)	1.364 (0.772 – 2.411)

† adjusted for age, gender, literacy, marital status and geographical region

#### d. Proportion of HIV related deaths in HIV infected family

The multiple logistic regression analysis against the dependent variable proportion of HIV related death in HIV infected family was compared with CHBC and control group. As illustrated in Table 49, the adjusted OR comparing CHBC with control was close to 1 (OR=0.99) indicating no difference.

Table 47. Association of intervention group (CHBC group versus control group) with HIV related deaths in HIV infected family in multiple logistic regression

	HIV related deaths in HIV infected family
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: control group)	0.99 (0.93 – 1.1)

† adjusted for age, gender, literacy, marital status and geographical region

### III. Psycho-social

Psycho-social outcomes were measured on the following indicators: perceived material and inter-relational social support, disclosure, agency (self-confidence) and perceived stigma and discrimination.

#### a. Perceived support outcome

Two separate multiple logistic regressions analyzing the independent variable of interest (CHBC versus control group) with the two different dependent variables measuring perceived support: perceived satisfaction with support from friend and family and satisfaction with having someone to talk to about their problems/worries were conducted. Comparing the CHBC group against control group showed no significant difference with the OR being close to 1 (Table 50). On the other hand, the odds of satisfaction with having someone to talk to about their problems was 1.8 times higher for the CHBC group than control group (significant) (Table 50). This shows that in districts with CHBC services, the PLHIV on ART were able to communicate and get support from the CHBC service providers regarding their problems/worries.

Table 48. Association of intervention group (CHBC group versus control group) with Perceived support outcomes in two separate multiple logistic regression models

Dependent variable	Satisfaction with support from family and friends	Satisfaction with having someone to talk to about problems/worries
	Adjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
CHBC group† (Ref: Control group)	1.01 (0.60 – 1.70)	1.82 (1.05 – 3.15)

† adjusted for age, gender, literacy, marital status and geographical region

### b. Disclosure

The multiple logistic regression analysis of the independent variable against the dependent disclosure variable (Table 51) shows that the CHBC group had four times higher odds of generally disclosing their HIV status in comparison to control group (adjusted OR=4.2). This was a highly significant difference between the two groups indicating that CHBC programs have improved environment and self-esteem of PLHIV being served to increase their chances of disclosing their status.

Table 49. Association of intervention group (CHBC group versus control group) with not disclosing HIV status in multivariable logistic regression

	Generally disclose their HIV status
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: Control group)	4.18 (2.40 – 7.27)

† adjusted for age, gender, literacy, marital status and geographical region

### c. Agency

Multiple linear regression with self-confidence scale of 1-10 as dependent variable was fitted in model. The findings displayed in Table 52 shows that the CHBC group rate their self-confidence slightly lower than the control group by about 0.4 points but no significant difference was observed.

Table 50. Multiple linear Regression analysis of Agency – self-confidence scale 1-10

	Agency – self-confidence scale 1-10	
	B (95% CI)	P Value
CHBC group† (Ref: Control )	-0.39 (-0.86, 0.08)	.10

† adjusted for age, gender, literacy, marital status and geographical region



#### d. Stigma and discrimination

Multiple logistic regression was conducted to analyze the difference in perceived S&D by the clients in the two groups (CHBC and control). Table 53 shows that the CHBC group had lower odds of not facing stigma and discrimination in past three months in comparison to control group (OR .954) and this value was not significant.

Table 51. Association of intervention group (CHBC group versus control group) with not having faced stigma and discrimination in past three months using multiple logistic regression

	Did not face Stigma and discrimination in past three months
	Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: Control group)	0.95 (0.46 – 1.97)

† adjusted for age, gender, literacy, marital status and geographical region

#### IV. Prevention/behavioral

##### *Safe sex knowledge*

A multiple logistic regression was conducted to analyze the difference between the two groups (CHBC and control) in their knowledge on all three ABC HIV transmission prevention indicators (A-abstinence, B- Being faithful to one partner and C- consistent and correct condom use). There was no significant difference observed between the two groups but the CHBC group had slightly lower odds with adjusted OR of 0.71 (Table 54).

Table 52. Association of intervention group (CHBC group versus control group) with the Safe sex knowledge on all three ABC indications in multiple logistic regression

	Safe sex knowledge on all ABC indicators
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: Control group)	0.71 (0.43 – 1.18)

† adjusted for age, gender, literacy, marital status and geographical region

##### *Safe sex application*

The dependent variable of consistent condom use in past year with most regular partner was analyzed against the two comparison groups in a multiple logistic regression model. The adjusted OR was close to 1, indicating no difference between the control and CHBC group (Table 55).

Table 53. Association of intervention group (CHBC group versus control group) with the consistent condom use with regular partner in multiple logistic regression

	Consistent condom use with regular partner
	Adjusted Odds Ratio (95% CI)
<b>CHBC group†</b> (Ref: CHBC group)	1.03 (0.42 – 2.50)

† adjusted for age, gender, literacy, marital status and geographical region.

## V. PROGRAM IMPLICATIONS AND RECOMMENDATIONS

The major program implication and recommendations that can be inferred from this assessment are as follows:

- The program data analysis showed gaps in coverage for several IAs indicating the need to regularly assess gaps and increase reach to PLHIV in program districts with low coverage. Need to consider reasons for low coverage such as human resources, geographical terrain, and pre-defined limited coverage area.
- The reporting and monitoring of deaths and retention by the IAs and the SI Unit needs further strengthening to better serve the needs of the PLHIV in each district. The program should continue to report on the core CHBC program indicators that have been integrated into the national M&E system.
- There needs to be an increase in human resources to provide the services to the PLHIV in need in a wider geographical area. A number of clients and stakeholders stated this requirement to ensure coverage and services to those PLHIV in need.
- Although decreasing, stigma and discrimination against PLHIV is still a major challenge that needs to be addressed at all levels (National, district, community and household level). As S&D was reported to be highest by community members who are neighbors of PLHIV (specially educated middle and upper class individuals), it is important to conduct awareness programs at the both the community and national level.
- The CHBC program managers/service providers and key informants raised the concern of late voluntary enrollment of PLHIV into CHBC. This was supported by the findings of more perceived severe physical symptoms among the CHBC PLHIV clients. CHBC teams need to strengthen the co-ordination with other HIV service providers and organizations to identify and enroll the PLHIV in early stages after their HIV diagnosis.
- The CHBC program had proactively established networks and referral relationships with the different organizations in the community to address the vast social and economic needs of CHBC clients. These referral relationships resulted in addressing the different social and economic needs of clients resulting in the improved quality of life of CHBC clients. However, CHBC programs should explore opportunities to diversify linkages to social and economic support. CHBC should explore access to key services for children, who are orphaned or vulnerable, for example, community assistance with economic and psychosocial support, education, nutrition, etc.
- During the CHBC program quality assessment using the QA/QI checklist, it was observed that several CHBC service providers had limited knowledge and skills in caring for HIV infected and affected children. This is partly due to the fact that the current CHBC basic training manual does not include a specific session on pediatric

HIV care services. Hence, the program needs to enhance knowledge and skills through the revision of the current manual to include a pediatric care component.

- All stakeholders should help build national ownership for CHBC, which is currently being run by various I/NGOs. This can be done through a national planning process and by strengthening the relationship between CHBC services, DACC and local public health sector through the DPHO.
- The ART adherence reported by CHBC PLHIV on ART clients was good but still less than 95%. Hence, the ART adherence of PLHIV on ART, needs to be strengthened further through regular monitoring and counseling by CHBC teams to both the PLHIV care receiver and their family caregivers.
- The CHBC clients had better perceived psychological and environment quality of life domains, higher rate of disclosure and reported getting satisfactory social support from the CHBC teams. This indicates the benefits of CHBC programs and the need to expand to a wider geographical area where services are not being provided to the PLHIV in need.
- The comparative analysis of the intervention group (CHBC program) with a control group had several limitations. Hence, baseline information in program districts would provide a means to track progress of CHBC clients in the future.

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## **Annex 1. QA/QI Checklist findings by Implementing Agency (Objective 2 key findings)**

### **Gangotri (Achham):**

The Gangotri assessment revealed that they are performing well. They are providing CHBC services in Achham district and in some instances are also serving some clients of a nearby district. Overall, they had mobilized community support for the CHBC program in their work areas and this could be further strengthened. Most of the CHBC team members who are engaged in exposure prone procedures have received hepatitis B vaccinations. Some CHBC Kit bags were found to be missing some items.

### **Junkiri (Banke):**

Banke QA/QI assessment showed that overall, Junkiri is performing well and their CHBC teams are doing a good job in the community. They are working very hard to improve their performance against targets in CHBC, according to their reporting. They are coordinating with NSARC clinic for the disinfection of instruments and waste disposal. A few supplies were found to be missing from the CHBC Kit bags used by some teams. Client visits were regular and as per client need.

### **Community Development Forum (CDF) (Doti):**

The report from the field research feedback showed that CDF was carrying out CHBC services very efficiently. They appeared to have good services in terms of services provided, homecare visits, quality of services etc. They reported overall adherence to all the checklist items except for Hepatitis B vaccination by all CHBC team members engaged in exposure prone procedures. Some CHBC kits were missing a few supplies for some teams.

### **Asha Kiran Pratisthan (AKP) (Kailali):**

Asha Kiran Partisthan (AKP) QA/QI report showed them providing a satisfactory level of service to their clients. Their CHBC team reported that they have limited skills in pediatric care for HIV. Hepatitis B vaccination for providers needs improvement. A few supplies were found missing from some CHBC team kit bags.

### **Nepal National Social Welfare Association (NNSWA) (Kanchanpur):**

NNSWA QA/QI checklist assessment showed that overall performance of this organization was very good and they were performing as per community expectations. They were observed to have addressed all the requirements in the checklist. The assessment revealed that their CHBC team had limited knowledge and skills in pediatric HIV case handling. The CHBC kits bags were also lacking in a few supplies.

### **Naulo Ghumti (NGN) (Kaski):**

Naulo Ghumti was also carrying out CHBC activities at a satisfactory level. Client home visits were carried out on a regular basis as per requirements. Most of the required CHBC supplies were available and both CHBC teams and the community was satisfied with the services provided by NG. It was observed that the CHBC teams at NG were not always involving family members. The CHBC teams were not very involved in leading/participating in M&E data analysis and using information to adapt the findings.

**INF Paluwa (Kaski):**

INF was found to be generally carrying out its CHBC program at a satisfactory level and catering to requirements of clients in the VDCs they covered. Home visits were made according to client need. For post-partum problems, clients were referred to hospitals. Nutrition assessments, ART assessments and pediatric HIV assessments were observed to be covered during home visits.

**Youth Vision (Kathmandu):**

Kathmandu CHBC program was strong in all aspects. All CHBC staff had received the required basic and refresher training and had a plan of action in place. Personal files were maintained and home care supplies maintenance was carried out using the 'first in first out' (FIFO) method. Most consumables were available except for some vitamins. Data analysis was carried out during quarterly review meetings.

**BIJAM (Parsa):**

BIJAM was carrying out its CHBC program at a generally satisfactory level, as per the QA/QI checklist assessments. The overall services were in line with the criteria and guidelines provided. Hepatitis B vaccination was not received by all staff engaged in Hepatitis prone procedures. Masks and gloves were not available to all members. Pediatric linkage support was not observed.

**Namuna Integrated Development Council (Namuna) (Rupandehi):**

In Rupandehi, the IA appeared to be implementing its CHBC program quite well from all required aspects. They reported overall satisfactory checklist adherence except for missing CHBC supplies such as rubbing alcohol in a kit bag. They were found to be conducting home visits as per the SOP and client need.

**SPARSHA Nepal (Lalitpur):**

Sparsha Nepal was carrying out its CHBC programs efficiently. They reported carrying out quarterly meetings on regular basis to conduct participatory team analysis of program data. Linkages were done for pediatric HIV management. A few CHBC supplies were found missing from the CHBC kit bags. Field researchers reported that during the home visits they observed, the CHBC team interacted with the PLHIV clients only and not with family or caregivers.

**DPG (Sunsari):**

The DPG CHBC program overall adhered to the checklist items in carrying out its activities. Most of the checklist requirements were adhered to. Some of the CHBC personnel had not received hepatitis B vaccination. Some CHBC supplies were in low supply or missing. Researchers observed that CHBC staff had limited pediatric knowledge and skills.

**Social Awareness Center (SAC) (Surkhet):**

Surkhet CHBC assessment was exemplary and they appeared to be implementing the CHBC program quite well from all required aspects.

## **Annex 2. Implementing Agency wise assessment of extent of CHBC quality (In-depth group interviews and FGDs)**

### **Achham: In-Depth- Interviews with PMs and KI**

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#### **Program Managers: Gangotri**

In their opinion, CHBC was helping the community and the overall QoL of PLHIV in their district was satisfactory. They also stated that while CHBC is very important for PLHIV, the reach is still low. Due to lack of sufficient human resources they are not able to reach every VDC in the district. They felt the emotional stability of the PLHIV had increased as a result of an increased self-confidence within the PLHIV community. They mentioned that the clients receiving their HIV positive test results were quite slow to open up in the beginning. They said that discrimination existed but was less than before and was usually by “upper” educated people. They were satisfied with the government support. They felt that CHBC should build linkages to different services needed for the PLHIV. They suggested providing skill-based training to PLHIV to help them become more self-reliant.

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#### **Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

They were well aware of the CHBC program and the services provided. They felt that this program is important and should be expanded to all VDCs in the districts. They were aware of different organizations Providing CHBC programs in the district. In terms of QoL, they felt that the PLHIV health status has improved, and new economic programs, which CHBC program helped to link the PLHIV community with, is helping. They felt that PLHIV community is more self- confident now compared to before. They felt that discrimination was not an issue in their districts. The suggestion was made to increase training and human resources and to have greater national ownership for CHBC programming.



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**Banke: In-Depth- Interviews with PMs and KI**

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**Program Managers: Junkiri**

They stated that due to the CHBC program, there have been drastic changes in the emotional state of PLHIV. PLHIV who previously didn't opt for CHBC services are now coming forward. The program has helped bring the PLHIV community forward to participate in various programs and trainings. Children were linked with educational support and community members were more aware of HIV and the issues faced by PLHIV. However, they felt that self-reliance on health matters was still an issue and that CHBC was not able to fulfill expectations. Further, transport support and rehabilitation services were not supported by CHBC. They also emphasized that S&D existed in the hospitals as well and in some cases, PLHIV were not treated like other non-PLHIV patients. Many community members still didn't have adequate knowledge about HIV and therefore continuing community awareness programs were required. They also recommended that there should be transportation facilities for CHBC clients in an emergency, income generating programs, investment in education, more doctors to treat the PLHIV who are sick, more programs for community awareness, skill development trainings for single women, among others.

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**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

Key informants were aware of the CHBC program and said that CHBC program has been targeted to help PLHIV clients and provided door to door care services and client referral, carried out regular visit to "solve problems" created after using ART. Further, they said that CHBC helped to minimize discrimination and ensure regular intake of (ART) medication. In most of the cases, the clients come to ART clinics, when very ill. They were of the opinion that the government has been helping the program to some extent and were happy that NCASC has provided 15 different types of HIV related tests for free of cost at ART clinic, which has helped the PLHIV community. They mentioned that due to the CHBC program, PLHIV feel they can live as other normal people and QoL of PLHIV has improved quite a bit, especially due to CHBC and ART clinics. Their suggestion to improve CHBC was that nutritional and financial support should be increased. In terms of stigma and discrimination, they felt that negative thinking from the side of PLHIV has decreased, and so has feeling of discrimination by the community as a result of the CHBC program. They felt that CHBC program was important and should reach all PLHIVs in the district. They were of the opinion that both the government and the NGOs were supporting CHBC programs equally.

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**Doti: FGD with CHBC Client and CHBC Caregiver**

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**CHBC Client**

Satisfaction level with CHBC was generally good amongst all members in the FGD at CDF. The clients stated that the CHBC team visited them regularly, and when they did, they were well presented and very helpful. They were happy to disclose their HIV status mainly due to the support they felt from the CHBC team. They generally felt that the services matched their needs, which included key services such as hygiene, safe sex, safe injecting practices, support with regular health check-up for symptoms, support with ART medication, information sharing on safe sexual practice, and food habits among others. S&D was not severe, but did exist in some cases according to them. They felt that the visits by the CHBC team were infrequent ranging from 2-3times/year to once a year and need to be strengthened. According to them, QoL of PLHIV in Doti was good, and self-confidence was higher than before. Their perception of their health and well-being was high; better than when they first sought CHBC support.

**CHBC Caregivers**

Doti Caregivers did not provide extensive information during FGDs. The participants stated that the condition of PLHIV had improved in the recent years and the number of clients utilizing CHBC services had also increased. They felt that this was due to the increased awareness by PLHIV community. The respondents had received some type of training on CHBC care, and some had received the training on more than one occasion. They mentioned that they helped the CHBC clients by reminding them to take medication on time, providing information on better hygiene, and providing information on better eating habits, as well as helping with childcare. Discrimination appeared to be a recurring issue although most felt that it was better now than before. They said that even caregivers were discriminated against at times. They felt a need for enhanced vocational training for the PLHIV community.

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**Doti: In-Depth- Interviews with PMs and KI**

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**Program Managers: Community Development Forum (CDF)**

In CDF, there were four teams working in 33 VDCs which provided daily home visits. The respondents felt that this program is helping PLHIV and should be continued. They were concerned about the continuation of such programs in future. Discrimination was found to be present although in less frequent than before. They were convinced that programs aimed at making PLHIVs self-dependent were effective. The program managers felt that the nutritional support linkage needed improvement also emphasized on limitation in human resources. The respondents felt that if emergency funds were provided it would help them with their activities in extreme cases such as death and funeral support.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

According to them, CDF was the only organization in their area looking after the CHBC activities. Psychological and medicinal support were also provided through CHBC. QoL of PLHIV was poor in Doti although it's better than before. The KI felt that human resources needed to be increased to expand CHBC services to other VDCs. Pediatric care as well as nutritional support needed to be addressed. Discrimination existed, less than before, and usually by educated "higher" level community members. Need based assessments should be stringently carried out.

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**Kailali: In-Depth- Interviews with PMs and KI**

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**Program Managers: Asha Kiran Pratisthan (AKP)**

PMs highlighted that PLHIVs were getting various types of support from VDC, municipality and DDC. The concern voiced by PMs was that clients normally came for CHBC service in later stage of HIV and not opted for service in the early stage, once after the diagnosis of HIV positive status. They requested that better awareness activities should be run so that clients could be referred to them earlier. They were particularly happy about the ambulance services being supported by ASHA Project for clients. They also felt that the clients were very happy in general with the services provided by CHBC. They said that the QoL of clients had improved due to CHBC service, but there was room for improvement such as increasing human resources in CHBC , providing homecare support to those coming from large distances, and increasing the number of doctors in ART clinics.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

In general, the key informants were aware of the CHBC programs in their community and the services offered. They were disappointed that PLHIVs contacted them for clinical services only after their CD4 count had gone down and were subsequently under medication due to secondary infections. The KI wished that clients could come before reaching this state. According to them, the PLHIV clients have become aware and have united for the benefits of the PLHIV community as a whole. They said that the clients discuss, raise awareness among themselves, and encourage each other to take medications on time and other services. They said the attitudes and thinking of the PLHIV have changed. For example they used to even contemplate suicide due to low self-esteem and discrimination but today the situation is different. The KI felt discrimination was still an issue but reduced compared to before. The only way to address S&D was to have programs aimed at raising awareness at the community level, in place. They were of the opinion that there was government support for the program.

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**Kanchanpur: In-Depth- Interviews with PMs and KI**

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**Program Managers: Nepal National Social Welfare Association (NNSWA)**

Their main concern was that stigma and discrimination still present in the community. They expressed that PLHIV clients should be referred to them in the early stages of HIV. They suggested increasing CHBC personnel and adding CD4 services in their ART site. They felt that CHBC was overall a very important program and should be prioritized based on the need of clients. The perception of national support for this group was that support was provided for the development of national guidelines.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

All those interviewed were well acquainted with CHBC programs in their district. They found the services provided by this program very important and effective for the PLHIV community. In their opinion, S&D existed at a medium level in the community. They felt that the government assistance focused on guideline development. They were of the opinion that HIV Program managers should also receive training on CHBC and number of trainings should be increased in their district. They felt that Care Homes for PLHIV required more attention from all the stakeholders.

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**Surkhet: In-Depth- Interviews with PMs and KI****Program Managers: Social Awareness Center (SAC)**

The PMs were aware of the ongoing PLHIV programs in the district. The common feeling regarding clients visiting them was that clients only came during the later stages when it is more difficult to look after their needs. The PMs felt that QoL of clients had improved since initiation of the CHBC program in their district and this was due to the fact that CHBC team was in regular contact with the PLHIV and they have been providing counseling about HIV/AIDS to the PLHIV and their families as well. They felt that unless more income generating programs were devised, the QoL would not improve. The emotional and social well-being according to them has increased over time, especially with the ART medications available to the community. The knowledge that HIV does not necessarily relate to immediate death has helped the PLHIV community feel better about themselves. According to them, national support has gradually increased in terms of providing ART, PMTCT and VCT. The biggest suggestion they had was to provide to CHBC services was to increase income generating programs as part of CHBC.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The participants were well aware of CHBC programs being run in their districts. They informed that CD4 counts, ART services and VCT services were some of the services being linked through CHBC programs. The overall perception of CHBC program was that it was a beneficial program for PLHIV community. They felt that the overall QoL of PLHIV was improving. Further, according to them, the emotional wellbeing of clients had increased due to CHBC. However, they felt that there was room for improvement and, as an example, they said a couple of NGOs had stopped their services because the program funding had finished. Thus they said that sustainable programs were required. They also said that discrimination and stigma was still ongoing in their district. Furthermore, they suggested that CHBC programs should be expanded by increasing human resources and also having community based CHBC programs rather than just PLHIV centered programs for awareness creation. They felt that networking between DACC, NCASC and NGOs also needed to be improved.

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**Kapilvastu:** In-Depth- Interviews with PMs and KI

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**Program Managers (Kapilvastu and Rupandehi): Namuna Integrated Development Council (NIDC)**

The CHBC program looked after physical, mental and emotional well-being of PLHIV clients. They felt that this program was helping the clients whether those came during early stage or at a later stage of HIV. The financial and human resource constraints were keeping CHBC program from running more efficiently. They felt that quality of life (QoL) of the PLHIV clients appeared to have improved over time. They suggested that while the government was trying to help the program greater national ownership was required. They requested increased human resources as well as nutrition support, along with transportation support for CHBC clients. They all felt that skill based training programs should be added and implemented to PLHIV clients.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The key informants were aware of the CHBC program in their district but were not clear about the actual number of PLHIV clients it catered to. They mentioned ART and CHBC as the main programs being run for PLHIV clients in their area with Namuna providing CHBC services and DPHO as the organization providing ART services. There was no doubt that KIs agreed that CHBC program was important program for PLHIV clients. The KIs stated that deaths in the district amongst PLHIV clients had started to go down as a result of CHBC services, as people became more aware with increased access to health services and support groups. However, they felt that CHBC services were lacking in human resource as well as in maintaining confidentiality. They felt strong national ownership would be even more effective. Lastly they stated that appropriate programs focusing on women's health and services should be implemented in order to help raise awareness for female PLHIV.

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**Rupandehi:** In-Depth- Interviews with KI

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**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

Key informants were generally aware of the CHBC program and were supportive of the program which they recognized as being an important support for PLHIV community. The KIs were aware of the different services being offered through CHBC and linkages to different services made such as ART, VCT, income generating services amongst others. They felt that many late stage clients came to them after returning from India (as migrant workers), and therefore they often could not do a lot to help them. They felt that emotionally and in terms of QoL, PLHIV community was doing better than before. Furthermore, they felt even the health workers themselves were ignorant on some health issues related to PLHIV. They wanted local health posts to also provide support to PLHIV clients. They suggested improving mass awareness programs as well as social mobilization programs to aid CHBC programs in their districts.

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**Kaski: In-Depth- Interviews with PMs and KI (Nauloghunti and INF)**

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**KASKI: NAULO GHUMTI Program Managers**

The interviewees were very knowledgeable on CHBC services in their area. They were clear about the program running in their area. They stated that since CHBC came to their district, there has been no need to go to Kathmandu, as they did before, and this has made a positive impact. Their perception of client QoL was also very high due to CHBC services. Furthermore, they stated that clients felt more empowered by having CHBC program in place. They stated that stigma and discrimination existed, and children too were discriminated against, at times.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The informants were aware of CHBC programs. They stated that ART and PMTCT services were the major services being linked through this program in Kaski. They said that the clients mostly came for services only when they experienced severe symptoms. They therefore wished that clients would come immediately after finding out about their HIV status. According to them, the QoL of the clients was satisfactory due to CHBC programs. According to them, the social and emotional wellbeing of PLHIV once were major problems but this is not so now due to this program and also due to the involvement of various other organizations and the national ownership. Similarly, stigma and discrimination issues were largely reduced but existed in some form or the other. They suggested training medical professionals, community members and other stakeholders in this area. They felt that national ownership was important and that CHBC should get the same status as TB program.

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**KASKI: INF Program Managers**

The service providers who were interviewed were aware of the CHBC program in their working area. It appeared that the clients normally came to them only when their health problems became unbearable for them to handle. They felt that emotionally, clients on CHBC were more in control of their lives and also in terms of their QoL. Regarding stigma and discrimination, the PM/SP felt that this is less than before due to the CHBC programs, but still issues existed in the traditional society. They felt community-targeted awareness programs such as street dramas needed to be implemented to further reduce S&D. They also suggested national ownership of CHBC programs similar to the TB and polio eradication program.

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**Parsa: In-Depth- Interviews with PMs and KI**

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**Program Managers: BIJAM**

The Program Managers felt that the CHBC program was being run in a satisfactory way. They mentioned BIJAM as one of the major organizations that supported PLHIV programs and conducted CHBC program in Parsa district. The program has helped the community in terms of linkages with education, psychosocial support, ART, VCT, medication, nutritional support and hygiene awareness. They felt that QoL of PLHIV clients has improved due to CHBC services. CHBC has maintained the confidentiality of clients. The interviewees stated that this program needs to be continued, and in order to be more effective, health checkups, skill based training and access to medication needed to be improved. Stigma and discrimination existed, and that needed to be addressed by raising awareness at the community level.

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The KI in Parsa were very aware of the issues related to the CHBC program. They informed that Bijam and DYC were two major NGOs working with PLHIV. They mentioned that Bijam provided CHBC services and had linkages with ART, VCT, and empowerment activities. They felt that the CHBC program was a very important part of PLHIV support and national ownership would increase coverage of CHBC. They felt that there were a number of overlaps between CHBC programs and other PLHIV support programs which led to less efficient implementation of services to the PLHIV community. Discrimination existed in the community at a lower level than before but needed to reduce further. For that they recommended street dramas, awareness programs etc. Lastly they suggested more frequent dispensing of ART from the ART sites and providing transportation for clients.

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**Kathmandu: In-Depth- Interviews with PMs and KI**

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**Program Managers: Youth Vision**

The program managers were very aware of the ongoing CHBC programs and the organizations conducting this service in Kathmandu. In terms of social and emotional development, major improvements have been noticed for example, increased awareness of self, ability and desire to discuss problems, health seeking behavior etc. The fact that PLHIV communities were now part of civil and government services have helped with this. They suggested that practical training should be provided for ART adherence. Job facilities and child support were also issues that they felt needed more addressing. Regarding stigma and discrimination they felt that orientation programs were required to deal with this. They felt that national ownership of the CHBC program could be strengthened by having more resources available. They suggested that different modalities of CHBC programs for urban and rural communities needed to be developed. Lastly they recommended PLHIV community needed to be involved in developing the new national health plan.

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**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The interviewees were well aware of CHBC program and its objectives. They felt that CHBC was being used by a larger number of clients via various NGOs working with PLHIVs in the city. They felt QoL of PLHIV clients had improved very much in the last few years, due to the united activities of number of NGOs, media and healthcare professionals. In terms of emotional and social development, they were of the opinion that PLHIV are now much more aware and in control of their lives. For this CHBC counseling had helped. Human resource, networking and the addition of viral load services were the key recommendations for strengthening CHBC services.

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**Lalitpur: In-Depth- Interviews with PMs and KI**

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**Program Managers: SPARSHA Nepal**

The program managers interviewed were well acquainted with CHBC programs, organizations and the services provided. Regarding ongoing CHBC programs with ASHA Project, they stated that initially, clients did not come for services due to fear of discrimination. However, now it is being used widely. The difficulty is in contacting the scattered population of PLHIVs around the district. They were aware of QoL and found that to be improving among clients. This was attributed to better knowledge of

**Key Informants: HIV clinic manager, DACC member and PLHIV support group members**

The Key informants interviewed in this district did not appear to be very informed or were not very responsive. For example one of the respondents in the interview stated that he had limited knowledge of CHBC. However the overall knowledge about the CHBC program was satisfactory in the sense that they understood certain aspects of the program. One of the interviewees did not know about CHBC at all. Among those who were more aware of the program they said that AHS Project and Youth Vision

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the disease, availability of medication, and the support services provided by various relevant organizations. Emotionally and socially, clients were observed to be much more at ease due to medications and support services. The interviewees reported that stigma and discrimination still existed in the community and felt that an awareness program was required to counter it. Their suggestion for improving CHBC programs was to involve all levels of community members including political and religious leaders. They were satisfied with national support.

were supporting CHBC programs. They felt that the CHBC program appeared to be helpful to PLHIV clients and it was being implemented. They felt that PLHIV were emotionally better off now and could talk about their problems more freely. They suggested that more awareness programs need to be developed for clients that were new to the program. Stigma and discrimination, according to them, was present in the community. They felt that awareness programs such as street dramas etc., would help and should be planned to reduce this. They felt that national ownership would provide more direct services to the PLHIV community.

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**Lalitpur: FGD with CHBC Client and CHBC Caregiver**

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**CHBC Client**

The perception of CHBC program and team was good. They were happy with the visits, interactions and discussions made by and with CHBC team. They received information on health and hygiene, safe sexual and safe injecting practices, monitoring of CD4 counts amongst others. However, the clients stated that CD4 count facility was not always available at the ART site due to technical problems. Regarding stigma and discrimination, clients were generally positive stating that this has reduced considerably. They said that they try to take ART as much as possible but seek support from colleagues to remember. Regarding emotional, spiritual counseling, they were satisfied with the services they were receiving. They were happy with the confidentiality as well as healthcare support provided to them in need. They felt that national ownership would provide support in a more holistic manner.

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**CHBC Caregiver**

The caregivers interviewed had received training on caring for the PLHIV clients from CHBC organizations. The caregivers were aware of health and hygiene, ART medication, nutritious diet, among other HIV related topics. They understood the need for ART adherence and regular checkups for the PLHIV. They were well aware of steps to be taken in case of an emergency situation e.g. to contact the service provider or take the client to the nearest health facility. They suggested that CHBC program should be taken to the entire community and not just to a limited population. Lastly, they suggested that even rural communities should have ART access.

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**Sunsari: In-Depth- Interviews with PMs and KI**

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**Program Managers: Dharan Positive Group (DPB)**

The program managers interviewed said that the CHBC program was providing services focusing on physical, mental, spiritual and social aspects. They were well aware of the CHBC program and were able to name and describe the activities of key organizations providing the service. They felt the CHBC program helped PLHIV clients in disclosing their HIV status, which would not have been possible otherwise. Being linked to skill based training has helped to raise the self-esteem of the PLHIV. The overall perception of CHBC in their opinion was that this service has allowed the PLHIV community to live freely and happily. However, despite the positive aspects of this program, stigma and discrimination was still not completely gone. There were examples of how even the pets of clients were being discriminated against. Their suggestions for better CHBC programs included transport facilities for CHBC clients as well as adding treatment and support services. They summarized by saying the CHBC program should never stop.

**Key Informants: HIV clinic manager, DACC member, PLHIV support group members**

Key Informants were aware of the types of programs being run in their districts. The programs that were being run included ART services, PMTCT, OI (TB, Diarrhea, Malnutrition). They were knowledgeable about ongoing CHBC programs and talked about two CHBC personnel conducting home visits in the districts. They talked about coordination between different organizations in providing services to clients. They provided examples (cited below) of success stories showing improved QoL of PLHIV. Social acceptance was taken as a clear sign of enhanced emotional improvement of clients. They suggested nutritional support as well as treatment support should be added to the CHBC program. In terms of stigma and discrimination, they said that it still existed and that educated people stigmatized and discriminated more.

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**Sunsari: FGD with CHBC Client and CHBC Caregiver**

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**CHBC Client**

Clients were generally satisfied with the CHBC team. The interactions with them were very positive. Clients were confident disclosing their HIV status saying that it was their right. In terms of their knowledge of nutrition, hygiene, positive prevention, safe sex, safe injecting practice etc., the PLHIV clients appeared to be well versed in all these. This was also observed for the ART medication regime where they clearly outlined all the important aspects. The clients felt that the CHBC teams were very proactive in supporting clients by linking them to different needed services and reducing stigma and discrimination issues in the community. Clients termed the support as “excellent”.

**CHBC Caregiver**

The caregivers that were interviewed stated that CHBC helped the PLHIV by caring and helping them reach medical services whenever required. However, they haven’t had any formal training themselves in CHBC. They had received informal orientations and suggestions from NGOs on caring for PLHIV. During home visits, they provided informal education and remedies for basic health problems. The caregivers were aware of ART adherence regimes. The caregivers that were interviewed agreed that discrimination was still an issue, something all of them had encountered at one point or another.

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### Annex 3. Study Tools

#### Annex 3.1. Questionnaire for CHBC service users and control groups

#### FHI Nepal CHBC Program Assessment

**Instructions**

- Informed consent for the study must have been obtained prior to administering this survey.
- Please ensure the section below has been fully completed.

<b>SURVEY ID Number</b>	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>				
<b>CHBC /Control Group SITE NAME:</b>	_____				
<b>CHBC /Control Group SITE CODE:</b>	_____				
<b>TODAY'S DATE:</b>	__ __ / __ __ / __ __  <b>dd/mm/yy</b>				
<b>INTERVIEWER NAME:</b>	_____				
<b>INTERVIEWER CODE:</b>	__   __				
<b>INFORMED CONSENT OBTAINED (Circle one)?</b>	<b>Yes = 1 No = 2 ← DON'T START UNTIL OBTAINED!</b>				
<b>SURVEY RESULT (Circle one)</b>	<b>Completed = 1 Partially Completed = 2 Other = 3</b>				

<b>Quality Control</b>			
Name Date	Survey Checked by Supervisor – Field Level	Control – FHI Kathmandu	Data Entry Clerk
	_____	_____	Initial Entry
	Supervisor Name	Name	Blind Entry
	____/____/____	____/____/____	_____
		Name	Name
		____/____/____	____/____/____
Remarks			

___ / ___ / hour
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**INSTRUCTIONS TO INTERVIEWER:** Have the patient answer each the questions below. For each of the questions, **enter the number** corresponding to the patient’s answer choice.

**READ TO THE PATIENT:** “My name is \_\_\_\_\_. Thank you so much for meeting with me today. The interview today will take about 60 minutes. We will start off today with some general questions about you and your life. Please remember that your answers are totally confidential. You can also skip any questions which you do not feel comfortable to answer, or end the interview at any time should you need to.

<i><b>SECTION 1: SOCIODEMOGRAPHIC &amp; ECONOMIC INFORMATION</b></i>			
<b>NO.</b>	<b>QUESTIONS AND FILTERS</b>	<b>CODING CATEGORIES</b>	<b>SKIP TO</b>
101	<i>RECORD THE SEX OF THE RESPONDENT</i>	Male 1 Female 2	
102	On what month and year were you born?  <i>Write in numbers for each category: Month and Year</i>	Month [__ __] Don't know 88 No response 99  Year [__ __] Don't know 88 No response 99	
103	How old are you?  <i>Compare and correct Q102 if needed</i>	Age in completed years [__ __] Don't know 88 No response 99  <b>ESTIMATE BEST ANSWER</b>	
104	What is the <b>highest level</b> of education you have completed?  <i>Circle one response code number</i>	Completed class_ [__ __] College, University <b>or Higher</b> 66 No formal education 77 Don't know 88 No response 99	
105	How many <b>total years</b> of education have you completed up to now?	# years completed [__ __] Don't know 88 No Response 99	
106	What is your current marital status?  <i>Circle one response code number</i>	Married 1 Never married 2 Divorced/separated 3 Widowed 4 No response 99	

107	<p>Where are you living now?</p> <p><i>(Clarify this is not their address but the whether or not they live in a house they own, rent, with family or with other people, or on the street)</i></p> <p><b>IF participant does not understand show possible answers. Circle one response code number</b></p>	<p>House I own 1  House I rent 2  In my parents/other family member's house 3  In a friend's house, other person's house 4  On the street 5  Other _____ 6  No response 99</p>	→ 1																														
108	<p>How many people live in your house including you (all people who have regularly eaten and slept in the house for the past 6 months)?</p> <p><b>Write in number</b></p>	<p>Number [__ __]  No response 99</p>																															
109	<p>Please list who you currently live with?</p> <p><b>Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p><b>M = Mentioned</b>  <b>NM = Not Mentioned</b></p> <table style="margin-left: auto; margin-right: auto;"> <thead> <tr> <th></th> <th style="text-align: center;"><u>M</u></th> <th style="text-align: center;"><u>NM</u></th> </tr> </thead> <tbody> <tr> <td>a) By myself</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>b) Partner/spouse</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>c) Parents</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>d) Siblings</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>e) Children</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>f) Relatives</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>g) Friends</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>h) Colleagues</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td>i) Other (specify) _____</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> </tbody> </table>		<u>M</u>	<u>NM</u>	a) By myself	1	2	b) Partner/spouse	1	2	c) Parents	1	2	d) Siblings	1	2	e) Children	1	2	f) Relatives	1	2	g) Friends	1	2	h) Colleagues	1	2	i) Other (specify) _____	1	2	
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f) Relatives	1	2																															
g) Friends	1	2																															
h) Colleagues	1	2																															
i) Other (specify) _____	1	2																															
110	<p>Do you have any children of your own (including natural and adopted ones)? Compare with item "Children" in Q. 109</p>	<p>Yes 1  No 2  No response 99</p>	→ 113 → 113																														
111	<p>How many children do you have?</p> <p><b>Circle one number</b></p>	<p>1  2  3  4  5  Other Number: _____  No response 99</p>																															
112	<p>What are their ages, starting from the eldest one?</p> <p><b>Write in ages</b></p>	<p>Age 1: ____  Age 2: ____  Age 3: ____  Age 4: ____  Age 5: ____  (If child less than 1 year of age round up to 1)</p>																															
113	<p>Do you work for money?  <i>(Explain can be formal or informal work and can be full or part time)</i></p>	<p>Yes 1  No 2  No response 99</p>	→ 117 → 117																														

114	Do you work on a full-time or part-time basis?  <i>Circle one response code number</i>						Full time work 1 Part time work 2 No response 99	
115	What type of work is your main source of income?  <i>Circle one response code number</i>						Farming 1 Fishing 2 Small business 3 Taxi driver 4 Street seller 5 CHBC staff 6 Peer educator 7 Government employee 8 Other _____ 88  No response 99	
116	Over past 6 months, please estimate how much money on average you <b>make</b> in a month.	_____					Don't know 88 No Response 99	
117	Over past 6 months, what was your household monthly income on average (not including that you yourself earn each month)? <i>(Explain: income from all resources legal, illegal – if they give a range, provide the average)</i>  <i>Write in amount</i>	_____					No response 99	
118	If you are not employed who is the main provider of financial support to you (ask this question only in case the answer to Q. 113 was “NO”)?  <i>Multiple supports are possible, Circle one response code number</i>						Partner/spouse 1 Parents 2 Siblings 3 Children 4 Relatives 5 Friends 6 Other (specify) _____ 7 No response 99	
119	What type of work was your main source of income before you were diagnosed with HIV?  <i>Circle one response code number</i>						Farming 1 Fishing 2 Small business 3 Taxi driver 4 Street seller 5 CHBC or OPC staff 6 Peer educator 7 Government employee 8 No job before 9 Other _____ 88  No response 99	
120	In the past six months, how often did <b>you</b> have enough money to afford:	Never	Once in a while	Fairly often	Very often	All the time	No answer	<b>Show answer categorie</b>

	a) Adequate food to eat	0	1	2	3	4	8	<b>s on card</b>
	b) Basic transportation (regular transport around town, to/from work, to/from the OPC)	0	1	2	3	4	8	
	c) Needed medical care for your own	0	1	2	3	4	8	
	d) Schooling of your own or children (if have children)	0	1	2	3	4	8	
121	What <u>VDC</u> do you live in now?  <b>Write out names clearly</b>	VDC ( <i>specify</i> ) _____						
122	What <u>district</u> do you live in now?  <b>Write out names clearly</b>	District ( <i>specify</i> ) _____						
123	How long have you lived in this district?  <b>Write out number of years</b>	Number of years [__ __] Record '00' if less than 1 year No response 99						

**SECTION 2: CLINICAL HISTORY & PERCEPTION OF/EXPOSURE TO SERVICES**

Thank you for answering those questions. Now I would like to ask you about your general health and experiences with CHBC team

(Note to interviewers: The complete clinical history section will be completed based on patient files in Section 7.)

NO.	QUESTIONS AND FILTERS	CODING	SKIP TO
201	<p>When did you first test HIV positive?</p> <p><i>Write in numbers for categories: Month and Year</i></p>	<p>Month [__ __]                      Don't know month 88                      No response 99</p> <p>Year [__ __]                      Don't know year 88                      No response 99</p>	
202	<p>When did you first come to contact with this CHBC team for medical care?</p> <p><i>Write in numbers for categories: Day, Month and Year</i></p> <p><b>DOUBLE CHECK IN PATIENT FILE</b></p> <p><i>For non CHBC clients ask following question</i></p> <p>Have you ever met with CHBC team?</p>	<p>Day [__ __]                      Don't know day 88                      No response 99</p> <p>Month [__ __]                      Don't know month 88                      No response 99</p> <p>Year [__ __]                      Don't know year 88                      No response 99</p> <p>Yes 1                      No 2                      No response 99</p>	
203	<p>Are you currently taking ART?</p> <p><i>Circle one response code number</i></p> <p><b>DOUBLE CHECK IN PATIENT FILE</b></p>	<p>Yes 1                      No 2                      Don't know 88                      No response 99</p>	<p>→ 210                      → 210</p>
204	<p>When did you first start taking ART?</p> <p><i>Write in numbers for categories: Day, Month and Year</i></p> <p><b>DOUBLE CHECK IN PATIENT FILE</b></p> <p><b>NOTE! If patient has only been taking ART three months or less skip to question 209 after completing 205-206</b></p>	<p>Day [__ __]                      Don't know day 88                      No response 99</p> <p>Month [__ __]                      Don't know month 88                      No response 99</p> <p>Year [__ __]                      Don't know year 88                      No response 99</p>	
205	<p>Did you experience any side-effects during the first three months of taking ART?</p>	<p>Yes 1                      No 2                      Don't know 88</p>	<p>→ 209                      → 207</p>



	<p><i>Circle one response code number</i></p> <p><i>If PLHIV has been taking ART less than 3 months, the question still applies. Ask if they have experienced any side-effects during whatever time they have been on ART.</i></p>	No response 99																																																																						
206	<p>Please list the side effects you experienced when first taking ART.</p> <p>SHOW POSSIBLE SIDE-EFFECT ANSWERS</p> <p><i>For each of the response choices, either '1' or '2' must be circled.</i></p>	<p><b>M = Mentioned</b> <b>NM = Not Mentioned</b></p> <table> <thead> <tr> <th></th> <th><u>M</u></th> <th><u>NM</u></th> </tr> </thead> <tbody> <tr><td>Pain</td><td>1</td><td>2</td></tr> <tr><td>Nausea</td><td>1</td><td>2</td></tr> <tr><td>Vomiting</td><td>1</td><td>2</td></tr> <tr><td>Diarrhea</td><td>1</td><td>2</td></tr> <tr><td>Itchy skin</td><td>1</td><td>2</td></tr> <tr><td>Tingly or shooting pain (like pins &amp; needles)</td><td>1</td><td>2</td></tr> <tr><td>Dizziness</td><td>1</td><td>2</td></tr> <tr><td>Fatigue</td><td>1</td><td>2</td></tr> <tr><td>Difficulty sleeping</td><td>1</td><td>2</td></tr> <tr><td>Lack of appetite</td><td>1</td><td>2</td></tr> <tr><td>Coughing</td><td>1</td><td>2</td></tr> <tr><td>Difficulty breathing</td><td>1</td><td>2</td></tr> <tr><td>Bad dreams</td><td>1</td><td>2</td></tr> <tr><td>Feeling sad</td><td>1</td><td>2</td></tr> <tr><td>Feeling anxious</td><td>1</td><td>2</td></tr> <tr><td>Headache</td><td>1</td><td>2</td></tr> <tr><td>Backache</td><td>1</td><td>2</td></tr> <tr><td>Other (specify) _____</td><td>1</td><td>2</td></tr> <tr><td>Other _____</td><td>1</td><td>2</td></tr> <tr><td>Other _____</td><td>1</td><td>2</td></tr> <tr><td>Don't remember</td><td>88</td><td></td></tr> <tr><td>No response</td><td>99</td><td></td></tr> </tbody> </table>		<u>M</u>	<u>NM</u>	Pain	1	2	Nausea	1	2	Vomiting	1	2	Diarrhea	1	2	Itchy skin	1	2	Tingly or shooting pain (like pins & needles)	1	2	Dizziness	1	2	Fatigue	1	2	Difficulty sleeping	1	2	Lack of appetite	1	2	Coughing	1	2	Difficulty breathing	1	2	Bad dreams	1	2	Feeling sad	1	2	Feeling anxious	1	2	Headache	1	2	Backache	1	2	Other (specify) _____	1	2	Other _____	1	2	Other _____	1	2	Don't remember	88		No response	99		
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207	<p>In the <u>past month</u>, did you experience any side effects from ART?</p> <p>If the patient has only been on</p>	<table> <tbody> <tr><td>Yes</td><td>1</td></tr> <tr><td>No</td><td>2</td></tr> <tr><td>Don't know</td><td>88</td></tr> <tr><td>No response</td><td>99</td></tr> </tbody> </table>	Yes	1	No	2	Don't know	88	No response	99	<p>→ 209</p> <p>→ 209</p>																																																													
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208	<p>Which ones?</p> <p>SHOW POSSIBLE SIDE-EFFECT ANSWERS</p> <p><i>For each of the response choices, either '1' or '2' must be circled.</i></p>	<p><b>M = Mentioned</b> <b>NM = Not Mentioned</b></p> <table> <thead> <tr> <th></th> <th><u>M</u></th> <th><u>NM</u></th> </tr> </thead> <tbody> <tr><td>Pain</td><td>1</td><td>2</td></tr> <tr><td>Nausea</td><td>1</td><td>2</td></tr> <tr><td>Vomiting</td><td>1</td><td>2</td></tr> <tr><td>Diarrhea</td><td>1</td><td>2</td></tr> <tr><td>Itchy skin</td><td>1</td><td>2</td></tr> <tr><td>Tingly or shooting pain (like pins &amp; needles)</td><td>1</td><td>2</td></tr> <tr><td>Dizziness</td><td>1</td><td>2</td></tr> <tr><td>Fatigue</td><td>1</td><td>2</td></tr> <tr><td>Difficulty sleeping</td><td>1</td><td>2</td></tr> <tr><td>Lack of appetite</td><td>1</td><td>2</td></tr> <tr><td>Coughing</td><td>1</td><td>2</td></tr> </tbody> </table>		<u>M</u>	<u>NM</u>	Pain	1	2	Nausea	1	2	Vomiting	1	2	Diarrhea	1	2	Itchy skin	1	2	Tingly or shooting pain (like pins & needles)	1	2	Dizziness	1	2	Fatigue	1	2	Difficulty sleeping	1	2	Lack of appetite	1	2	Coughing	1	2																																		
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209	It is normal to forget to take ARV medicines some of the time. Can you tell me how often in the <u>past week</u> you forgot to take your ARV medicines: (please remember all these answers are confidential...please answer this question honestly...):  <i>Circle one response code number</i>	Remembered to take all ARVs 1 Forgot <u>one</u> time 2 Forgot <u>two</u> times 3 Forgot <u>three</u> times 4 Forgot <u>four</u> times 5 Other: _____ (Write in number)  Don't know 88 No response 99																													
210	How has your health been generally in the past month?  <i>Circle one response code number</i>	Very good 1 Good 2 Not good, not bad 3 Poor 4 Very poor 5 No response 99																													
211	Does your health now limit you in any of activities such as:  a) Vigorous activity such as running, picking up heavy things, playing sports b) Moderate activity like carrying a bag or going on a walk c) Walking uphill (or climbing up a few flights of stairs) d) Bending down, lifting or stooping e) Walking around the house f) Bathing, eating, dressing or using the toilet.	<table border="1"> <thead> <tr> <th>Yes, a lot</th> <th>Yes, a little</th> <th>No</th> <th>No Response</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>99</td> </tr> </tbody> </table>	Yes, a lot	Yes, a little	No	No Response	1	2	3	99	1	2	3	99	1	2	3	99	1	2	3	99	1	2	3	99	1	2	3	99	
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212	Does your health impact upon your ability to work or find a job?	Yes 1 No 2 No Response 99																													
Now I'd like to ask you some general questions about your experiences with the CHBC and other services....																															
213	In the past <u>three months</u> , what services have you received from the CHBC or any	<b>M = Mentioned</b> <b>NM = Not Mentioned</b>																													

	<p>other services? Please try to think about all the different kinds of support you receive from the OPC at the clinic and community level.</p> <p><b>Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others; probe until the respondent feels they have provided you with all the information)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;"><b><u>M</u> <u>NM</u></b></p> <p>a) Clinical care 1 2 b) ART 1 2 c) Adherence counseling 1 2 d) PLHIV support group 1 2 e) Emotional counseling for me 1 2 f) Emotional counseling for my family 1 2 g) Nutritional support for me 1 2 h) Employment assistance for me 1 2 i) Referral support for me 1 2 j) Child emotional support 1 2 k) Child nutrition support 1 2 l) Child health care 1 2 m) Child schooling support 1 2 n) Play group for children 1 2 o) Support for transportation 1 2 p) Other (<i>specify</i>) _____ 1 2 Other _____ 1 2 Other _____ 1 2 Don't know 88 No response 99</p>	
214	<p>How comfortable are you in discussing your health concerns with the CHBC/other service providing staff?</p> <p><b>Show answer card</b> <b>Circle one response code number</b></p>	<p>Not at all comfortable 1 A little comfortable 2 Comfortable 3 Very comfortable 4 Don't know 5 No response 99</p>	
215	<p>Please tell me how happy you are with the care you receive from the CHBC /other services? Please be honest. Your answer will be kept confidential.</p> <p><b>Show answer card</b> <b>Circle one response code number</b></p>	<p>Very happy 1 Happy 2 Unhappy 3 Very unhappy 4 Don't know 88 No response 99</p>	<p>→ 217 → 217 → 216 → 216</p>
216	<p>Please tell me if there are things about the CHBC/other services that you do not like?</p> <p><b>Circle all that are mentioned</b></p>	<p>Health care worker attitudes 1 2 Health care worker skills 1 2 HCWs does not spend enough time during the examination 1 2 Stigma and discrimination 1 2 Medicines provided 1 2 Treatment was not successful 1 2 Information provided 1 2 Problems with transportation to the clinic 1 2 Other (<i>specify</i>): _____ 1 2 There is nothing I do not like 1 2 No response 99</p>	
217	<p>Please tell me some of the things about</p>	<p>Health care worker attitudes 1 2</p>	

	<p>the CHBC services you like/are happy with.</p>	<p>Health care worker skills 1 2  Medicines provided 1 2  Treatment was successful 1 2  Information provided 1 2  Peer PLHIV providers 1 2  Comprehensive services 1 2  Other (specify): _____ 1 2  No response 99</p>	
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### SECTION 3: PAIN AND OTHER SYMPTOMS

These questions are related to your physical wellbeing. **There are no right or wrong answers and please tell us how you have been feeling physically in the past month.** For each symptom or problem I read out, I will ask you how severe the problem was, how often you had it and how much it distressed or bothered you. Please remember that your answers are entirely confidential.

**Note:** *Please use the visual scale to explain and indicate the choice options to patient*, do **NOT** read out the ‘No response’ category. Only select this choice if the patient refuses to answer the question.

**During the past MONTH, did you have any of the following symptoms?**

#### Section 1

	Symptoms	Did not have	<b>IF YES</b> How <b>OFTEN</b> did you have it?				<b>IF YES</b> How <b>SEVERE</b> was it usually?				<b>IF YES</b> How much did it <b>DISTRESS</b> or <b>BOTHER</b> you??					No Response
			Rarely	Occasionally	Frequently	Almost constantly	Slight	Moderate	Severe	Very Severe	Not at all	A little bit	Somewhat	Quite a bit	Very much	
			1	2	3	4	1	2	3	4	0	1	2	3	4	
3.101	Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.102	Pain (if yes, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.103	Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.104	Cough		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.105	Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.106	Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.107	Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.108	Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.109	Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.110	Numbness/shooting pain/tingling in hands/feet (if shooting pain, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.111	Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.112	Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.113	Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4	99

3.114	Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.115	Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.116	Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.117	Sweating		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.118	Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.119	Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.120	Itching		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.121	Lack of appetite (don't feel like eating)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.122	Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.123	Difficulty swallowing; painful swallowing (if painful swallowing, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.124	Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.125	Headache (if yes, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.126	Backache (if yes, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.127	Problems with vision		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.128	Painful skin rash (if yes, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.129	Trouble with teeth; painful teeth (if painful teeth, continue to 3.201 after completing all section 1 and 2)		1	2	3	4	1	2	3	4	0	1	2	3	4	99
3.130	Vaginal or penile discharge		1	2	3	4	1	2	3	4	0	1	2	3	4	99

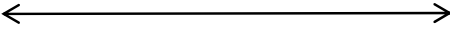
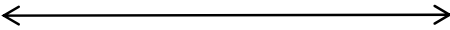

Section 2												
	Symptoms	Did not have	<u>IF YES</u> How SEVERE was it usually?				<u>IF YES</u> How much did it DISTRESS or BOTHER you??					No Response
			Slight	Moderate	Severe	Very Severe	Not at all	A little bit	Somewhat	Quite a bit	Very much	
3.131	Mouth sores		1	2	3	4	0	1	2	3	4	99
3.132	Change in the way food tastes		1	2	3	4	0	1	2	3	4	99
3.133	Hair loss		1	2	3	4	0	1	2	3	4	99
3.134	Constipation		1	2	3	4	0	1	2	3	4	99
3.135	Swelling or arms of legs		1	2	3	4	0	1	2	3	4	99
3.136	Changes in shape of body (eg face, limbs, buttocks)		1	2	3	4	0	1	2	3	4	99
3.137	Changes in skin		1	2	3	4	0	1	2	3	4	99
<b>If you have had any other symptoms in the past month, please list below and indicate how SEVERE it was and how much the symptom DISTRESSED or BOTHERED you.</b>												
<b>Other (please specify)</b>												
3.138			1	2	3	4	0	1	2	3	4	99
3.139			1	2	3	4	0	1	2	3	4	99
3.140			1	2	3	4	0	1	2	3	4	99
3.141			1	2	3	4	0	1	2	3	4	99
3.142			1	2	3	4	0	1	2	3	4	99
3.143	When you experienced these symptoms, did you receive any medical care for them?		Yes 1 No 2 No response 99									→ 3.148
3.144	Who provided you with care?  <b>Probe. Do NOT read out answers.</b>  <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>		<u>MNM</u> a) ART 1 2 → 3.145 b) CHBC team 1 2 → 3.145 c) PLHIV group/peer 1 2 → 3.148 d) Family 1 2 → 3.148 e) Self 1 2 → 3.148 f) District hospital (not ART) 1 2 → 3.148 g) Private clinic 1 2 → 3.148  Other (specify): _____ 1 2 Don't know 88 No response 99									

3.145	After getting care, how much improvement was there in general in your symptoms?  <i>Circle one response code number</i>	Completely better 1 Mostly better 2 Somewhat better 3 Still have symptoms 4 Symptoms are worse 5 Don't know 88 No Response 99	
3.146	Were there any symptoms that did not improve much?	Yes 1 No 2 No response 99	→ 3.148
3.147	Which ones?  <b>Probe. Do NOT read out answers.</b>  <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>	<u><b>MNM</b></u> Difficulty concentrating 1 2 Pain 1 2 Lack of energy 1 2 Cough 1 2 Feeling nervous 1 2 Dry mouth 1 2 Nausea 1 2 Vomiting 1 2 Feeling drowsy 1 2 Numbness/shooting pain/tingling in hands/feet 1 2 Difficulty sleeping 1 2 Feeling bloated 1 2 Problems with urination 1 2 Shortness of breath 1 2 Diarrhea 1 2 Feeling sad 1 2 Sweating 1 2 Worrying 1 2 Problems with sexual interest or activity 1 2 Itching 1 2 Lack of appetite (don't feel like eating) 1 2 Dizziness 1 2 Difficulty swallowing 1 2 Feeling irritable 1 2 Headache 1 2 Backache 1 2 Problems with vision 1 2 Painful skin rash 1 2 Trouble with teeth; painful teeth 1 2 Vaginal or penile discharge 1 2 Mouth sores 1 2 Change taste 1 2 Hair loss 1 2 Constipation 1 2 Swelling or arms of legs 1 2 Changes in shape of body (eg face, limbs, buttocks) 1 2 Changes in skin 1 2 Other _____ 1 2	

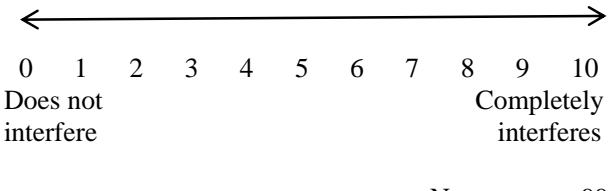
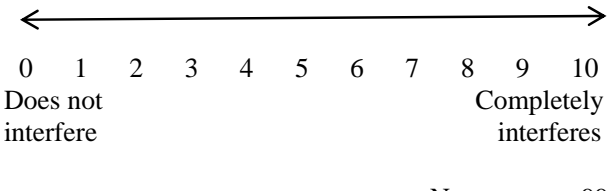
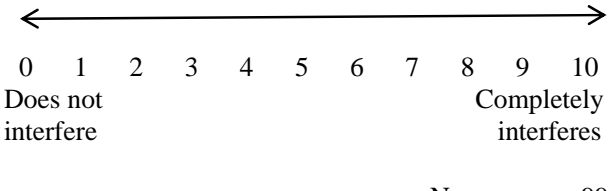
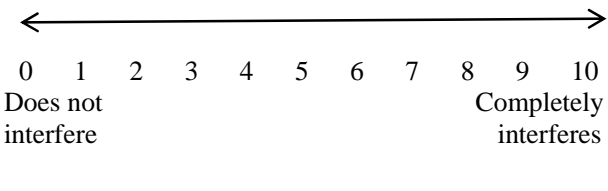
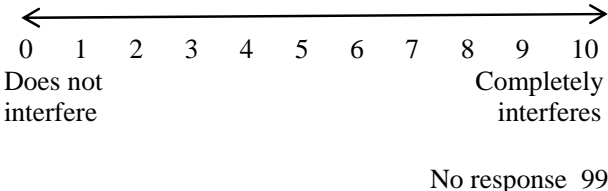
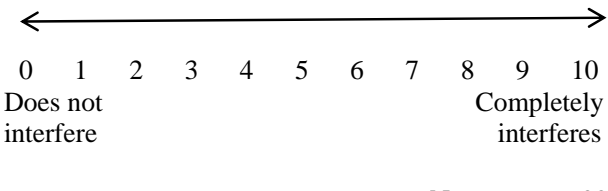
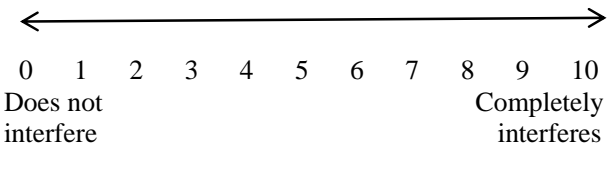


		Other _____ 1 2 Other _____ 1 2 No response 99	
3.149	Do you have any recommendations for improving the symptom care services provided by <b>CHBC teams</b> ?  <i>Open ended question/Fill in exact answer from respondent</i>		

<b>Section 3.2 PAIN</b>																																							
You mentioned you had pain in the <u>past month</u> . I will ask you some more questions about your pain in the <u>past month</u> . Some are yes and no questions. In some I will ask you to rank the pain by how severe it is. The scale goes from 0-10. 0 is no pain and 10 is the worst possible pain you can imagine. 5 is moderate pain.																																							
3.201	On the diagram please point to the areas on your body where you had or have pain.  <b>Show diagram and ask patient to point where they have pain on their body</b>  <i>Circle all that apply</i>	<b>Mentioned (M) Not mentioned (NM)</b> <table style="margin-left: auto; margin-right: auto;"> <thead> <tr> <th></th> <th><u>M</u></th> <th><u>NM</u></th> </tr> </thead> <tbody> <tr><td>Head</td><td>1</td><td>2</td></tr> <tr><td>Neck</td><td>1</td><td>2</td></tr> <tr><td>Hands</td><td>1</td><td>2</td></tr> <tr><td>Arms</td><td>1</td><td>2</td></tr> <tr><td>Torso</td><td>1</td><td>2</td></tr> <tr><td>Abdomen</td><td>1</td><td>2</td></tr> <tr><td>Genital area</td><td>1</td><td>2</td></tr> <tr><td>Legs</td><td>1</td><td>2</td></tr> <tr><td>Feet</td><td>1</td><td>2</td></tr> <tr><td>Other (specify) _____</td><td></td><td>88</td></tr> <tr><td>No response</td><td></td><td>99</td></tr> </tbody> </table>		<u>M</u>	<u>NM</u>	Head	1	2	Neck	1	2	Hands	1	2	Arms	1	2	Torso	1	2	Abdomen	1	2	Genital area	1	2	Legs	1	2	Feet	1	2	Other (specify) _____		88	No response		99	
	<u>M</u>	<u>NM</u>																																					
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Legs	1	2																																					
Feet	1	2																																					
Other (specify) _____		88																																					
No response		99																																					
3.202	Please rate your pain by pointing to the one number that best describes your pain at its <b>worst in the past month</b> .  <i>Show patient 10-point scale and ask them to tell you what number there pain was/is</i>  <i>Circle one response code number</i>	<p style="text-align: center;">←—————→</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p> <p style="text-align: center;">No Pain <span style="float: right;">Pain as bad as you can imagine</span></p> <p style="text-align: right;">No response 99</p>																																					
3.203	Please rate your pain by pointing to the one number that best describes your pain at its <b>least in the past month</b> .  <i>Show patient 10-point scale and ask them to tell you what number their pain was/is</i>	<p style="text-align: center;">←—————→</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p> <p style="text-align: center;">No Pain <span style="float: right;">Pain as bad as you can imagine</span></p>																																					

	<i>Circle one response code number</i>	No response 99	
3.204	<p>Please rate your pain by pointing to the one number that best describes your pain <b><u>on average</u></b>.</p> <p><i>Show patient 10-point scale and ask them to tell you what number their pain was/is</i></p> <p><i>Circle one response code number</i></p>	 <p>0 1 2 3 4 5 6 7 8 9 10  No Pain Pain as bad as you can imagine</p>	
3.204	<p>Please rate your pain by pointing to the one number that best describes your pain <b><u>right now</u></b>.</p> <p><i>Show patient 10-point scale and ask them to tell you what number their pain was/is</i></p> <p><i>Circle one response code number</i></p>	 <p>0 1 2 3 4 5 6 7 8 9 10  No Pain Pain as bad as you can imagine</p> <p>No response 99</p>	
3.205	<p>What treatments or medications are you using for your pain?</p> <p><b>Show answer card</b></p>	Paracetamol 1 Aspirin 2 Ibuprofen 3 Paracetamol/Codeine 4 Oral morphine 5 Injectable morphine 6 Traditional medicine 7 Other (specify): _____ 8 No response 99	
3.206	<p>In the <u>past month</u>, how much relief have pain treatments or medicines provided? Please point to one percentage that most shows how much relief you have received.</p> <p><i>Show patient 10-point percentage scale and ask them to tell you what number their pain was reduced by</i></p> <p><i>Circle one response code number</i></p>	 <p>0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%  No Complete Relief Relief  No response 99</p>	

**Now I'm going to ask you about the pain impact on your life in the past month:  
Indicate the number in the past month that best describes how pain has interfered with the following:**

3.207	General activity		
3.208	Mood		
3.209	Walking ability		
3.210	Normal work (includes both work outside the home and housework)		
3.211	Relations with other people		
3.212	Sleep		
3.213	Enjoyment of life		

		No response 99	
3.214	<p>The medicine used to treat severe pain is morphine and medium pain codeine. Both of these medicines are opioids and are recommended by the MoH and WHO to treat moderate to severe pain.</p> <p>If the doctor prescribed these medicines for you, would you have any concerns about taking them?</p> <p><b>Circle one response code number</b></p>	<p>Yes 1 → 3.215  No 2 → 4.101  Don't know 88 → 4.101  No response 99</p>	
3.215	<p>What are your concerns about taking opioids to treat pain?</p> <p><b>Probe. Do NOT provide answers.</b></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p><b>MNM</b></p> <p>Fear addiction 1 2  Previously a DU/IDU and fear relapse 1 2  Fear arrest 1 2  Family will not understand 1 2  Fear side-effects 1 2  Other (specify): _____ 1 2  No response 99</p>	

#### SECTION 4: EMOTIONAL WELLBEING

These questions are related to your emotional wellbeing. **There are no right or wrong answers and please tell us how you have been feeling in the past month.** For each statement I read out, I will ask you whether the severity of the problem is 'Not at all', 'A little', "Quit a bit" or 'Extremely'. Please remember that your answers are entirely confidential.

**Note:** Please use the visual scale to explain and indicate the choice options to patient, do NOT read out the 'No response' category. Only select this choice if the patient refuses to answer the question.

		Not at all	A Little	Quite a Bit	Extremely	NR
4.101	Suddenly scared for no reason	1	2	3	4	99
4.102	Feeling fearful	1	2	3	4	99
4.103	Faintness, dizziness or weakness	1	2	3	4	99
4.104	Nervousness of shakiness inside	1	2	3	4	99
4.105	Heart pounding or racing	1	2	3	4	99
4.106	Trembling	1	2	3	4	99
4.107	Feeling tense or keyed up	1	2	3	4	99
4.108	Headaches	1	2	3	4	99
4.109	Spells of terror or panic	1	2	3	4	99
4.110	Feeling restless, can't sit still	1	2	3	4	99
4.111	Feeling low in energy, slowed down	1	2	3	4	99
4.112	Blaming yourself for things	1	2	3	4	99

4.113	Crying easily	1	2	3	4	99
4.114	Loss of sexual interest or pleasure	1	2	3	4	99
4.115	Poor appetite	1	2	3	4	99
4.116	Difficulty falling asleep, staying asleep	1	2	3	4	99
4.117	Feeling hopeless about the future	1	2	3	4	99
4.118	Feeling blue	1	2	3	4	99
4.119	Feeling lonely	1	2	3	4	99
4.120	Thoughts of ending your life	1	2	3	4	99
4.121	Feeling trapped or caught	1	2	3	4	99
4.122	Worrying too much about things	1	2	3	4	99
4.123	Feeling no interest in things	1	2	3	4	99
4.124	Feeling everything is an effort	1	2	3	4	99
4.125	Feelings of worthlessness	1	2	3	4	99
<b>4.2 Mental Health Service Needs and Perceptions</b>						
4.201	When you are feeling low is there anything you do to make yourself feel better?  <i>Circle one response code number</i>			Yes 1 No 2 No response 99		→ 4.203 → 4.203
4.202	What do you do to make yourself feel better?  <b>Probe. Do NOT read out answers.</b>  <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>			<b>M NM</b> Talk with family 1 2 Talk with friends 1 2 Go to PLHIV support group meetings 1 2 Talk with CHBC/ART staff 1 2 Seek counseling from CHBC/ART staff 1 2 Take medicine 1 2 Work 1 2 Sleep 1 2 Try to distract myself 1 2 Drink 1 2 Take drugs 1 2 Watch TV 1 2 Nothing 1 2 Other (specify): _____ 1 2 Other (specify): _____ 1 2 No response 99		
4.203	In the past 3 months, did you ever receive emotional counseling for the things that make you sad at the CHBC/ART clinic?			Yes 1 No 2 No response 99		→ 4.206
4.204	How many times in the past 3 months did you receive emotional counseling services at the CHBC/ART clinic?  <i>Write in number</i>			Number _____  No response 99		

4.205	How did the counseling you received make you feel?  <i>Circle one response code number</i>	A lot better 1 A little better 2 No change 3 Worse 4 Much worse 5 Don't know 88 No response 99	
4.206	In the past 3 months, did you ever receive a home-visit from the home-based care team?	Yes 1 No 2 Not Applicable 8 No response 99	→ 4.209 → 4.208
4.207	How many times were you visited by the home-based care team in the past 3 months?  <i>Write in number</i>	Number_____	No response 99
4.208	How did you feel after receiving the home-visit?  <i>Circle one response code number</i>	A lot better 1 A little better 2 No change 3 Worse 4 Much worse 5 Don't know 88 No response 99	
4.209	In the past three months, did you ever join a PLHIV support group meeting?	Yes 1 No 2 No response 99	→ 4.212
4.210	How many times did you join the support group meetings in the past 3 months?  <i>Write in number</i>	Number_____	No response 99
4.211	How did attending the meeting make you feel?  <i>Probe. Circle one response code number</i>	A lot better 1 A little better 2 No change 3 Worse 4 Much worse 5 Don't know 88 No response 99	
4.213	Do you have any recommendations for how to improve the emotional support services provided by <u>CHBC teams</u> ?  <i>Open ended question/Fill in exact answer from respondent</i>	Not relevant/did not receive this service 8 No response 99	

<b>SECTION 5: SOCIAL SUPPORT - AFFECTIVE AND INSTRUMENTAL; STIGMA AND DISCRIMINATION</b>			
<b>SECTION 5.1:</b>			
Now I would like to ask you about the type of support you feel you get from people in general (including family, friends, the OPC, etc). <b>There are no right or wrong answers and please tell us what you think.</b> Please remember that your answers are entirely confidential.			
5.101	How many people are so close to you that you can count on them to help you if you have serious problems?  <i>Write in number</i>	Number _____  Don't know 88 No response 99	
5.102	How easy is it if for you to get help from your neighbours should you need it?  <i>Circle one response</i>	Very easy 1 Easy 2 Not easy 3 Not very easy at all 4 Don't know 88 No response 99	
5.103	Now, I'm going to ask you whether you feel you get enough of support from friends and family:  Visits from friends and relatives  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
5.104	Get useful advice about important things in your life  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
5.105	Get chances to talk with someone about your problems or worries  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
5.106	Have people who care what happens to you  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
5.107	Get love and affection from people that you care about  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	

5.108	Get help when you need it from your family  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
5.109	Get help when you are sick  <i>Circle one response</i>	As much as I would like 1 Less than I would like 2 Much less than I would like 3 Never 4 Don't know 88 No response 99	
Now I'd like to ask you about your experiences with stigma and discrimination...			
5.110	In the past 3 months, did you ever feel you were discriminated against?	Yes 1 No 2 No Response 99	→ 5.113
5.111	How often did you feel discriminated against in the past 3 months?  <i>Circle one response</i>	Very often 1 Often 2 Once in a while 3 Not very often 4 No response 99	
5.112	Who discriminated against you?  <b>Probe. Do NOT read out answers.</b>  <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>	Parents 1 2 Spouse 1 2 Children 1 2 Other family members 1 2 Neighbors 1 2 People at work 1 2 People at the market 1 2 HIV clinic staff 1 2 Hospital staff 1 2 CHBC team 1 2 Children's school 1 2 Myself 1 2 Other_____1 2 Don't know 88 No response 99	
5.113	What did they do to make you feel discriminated against?  <b>Probe. Do NOT read out answers.</b>  <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>	Refused to let me eat with them 1 2 Talked behind my back/gossip 1 2 Stared at me 1 2 Said mean things to me 1 2 Not let my children go to school 1 2 Not provide me with health care 1 2 Refuse to sell something to me 1 2 Physically abused me 1 2 Other_____1 2 Don't know 88 No response 99	



5.114	<p>How do you cope with stigma and discrimination such as what you described?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p>Talk with family 1 2</p> <p>Talk with friends 1 2</p> <p>Go to PLHIV support group meetings 1 2</p> <p>Talk with CHBC/ART staff 1 2</p> <p>Seek counseling from CHBC/ART staff 1 2</p> <p>Talk with CHBC team 1 2</p> <p>Take medicine 1 2</p> <p>Work 1 2</p> <p>Sleep 1 2</p> <p>Try to distract myself 1 2</p> <p>Drink alcohol 1 2</p> <p>Take drugs 1 2</p> <p>Other (specify): _____ 1 2</p> <p>No response 99</p>	
Now, I'd like to ask you about any assistance you receive from people...			
5.115	<p>Do you receive any financial support from a welfare program?</p> <p>For example, money to help with food, schooling.</p>	<p>Yes 1</p> <p>No 2</p> <p>No response 99</p>	
5.116	<p>Which organization or group provides this support you mentioned?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p>NGOs 1 2</p> <p>People's committee 1 2</p> <p>Mothers Group/FCHV 1 2</p> <p>NAPN/NKP 1 2</p> <p>Red Cross 1 2</p> <p>ART Clinic 1 2</p> <p>CHBC team 1 2</p> <p>PLHIV support group 1 2</p> <p>FHI 1 2</p> <p>VDC/DPHO 1 2</p> <p>Other: _____</p> <p>Don't know 88</p> <p>No response 99</p>	
5.117	Do you receive any food support?	<p>Yes 1</p> <p>No 2</p> <p>No response 9</p>	
5.118	<p>Who provides this support?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p>DoLISA 1 2</p> <p>People's committee 1 2</p> <p>Women's Union 1 2</p> <p>CPFC 1 2</p> <p>Red Cross 1 2</p> <p>OPC 1 2</p> <p>CHBC team 1 2</p> <p>PLHIV support group 1 2</p> <p>FHI 1 2</p> <p>Other: _____ 1 2</p> <p>Don't know 88</p> <p>No response 99</p>	
5.119	Do you receive any support in finding a job or other income generation support?	<p>Yes 1</p> <p>No 2</p> <p>No response 99</p>	

5.120	<p>Who provides this support?  <b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;">NGOs 1 2          People's committee 1 2          Mothers Group/FCHV 1 2          NAPN/NKP 1 2          Red Cross 1 2          ART Clinic 1 2          CHBC team 1 2          PLHIV support group 1 2          FHI 1 2          VDC/DPHO 1 2          Other: _____          Don't know 88          No response 99</p>	
5.121	<p>Do you receive any schooling assistance for you children?</p>	<p style="text-align: right;">Yes 1          No 2          No response 99</p>	
5.122	<p>Who provides this support?  <b>Probe. Do NOT read out answers.</b></p> <p><b>(Multiple responses possible. After respondent answers, probe by asking for any others)</b></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;">NGOs 1 2          People's committee 1 2          Mothers Group/FCHV 1 2          NAPN/NKP 1 2          Red Cross 1 2          ART Clinic 1 2          CHBC team 1 2          PLHIV support group 1 2          FHI 1 2          VDC/DPHO 1 2          Other: _____          Don't know 88          No response 99</p>	
Now I'd like to ask you about your hopes and worries....			
5.123	<p>Can you tell me what things worry you most these days?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;"><b><u>MNM</u></b>          Finding a job 1 2          Getting married/having a family 1 2          What will happen to me/my health in the future 1 2          Not having access to ART 1 2          Getting enough food to eat 1 2          Feeling ill 1 2          Drug use 1 2          Death 1 2          Pain 1 2          My children's future 1 2          Being able to send my children to school 1 2          Being alone 1 2          Going to prison 1 2          Other: _____ 1 2          Nothing worries me 7          Don't know 88          No response 99</p>	

5.124	<p>Can you tell me what your greatest hopes are for your future?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;"><b><u>M</u> <u>NM</u></b></p> <p>Finding a job 1 2</p> <p>Getting married 1 2</p> <p>Having a baby 1 2</p> <p>Cure for HIV 1 2</p> <p>Children going to school 1 2</p> <p>Living for a long time 1 2</p> <p>Quitting drugs 1 2</p> <p>Being happy 1 2</p> <p>Being loved 1 2</p> <p>Feeling healthy 1 2</p> <p>Not feeling pain 1 2</p> <p>Other: _____ 1 2</p> <p>Don't know 88</p> <p>No response 99</p>	
5.125	<p>Can you tell me what types of support you might need from the CHBC/ART or others in order to reduce your worries and achieve your hopes for the future?</p> <p><b>Probe. Do NOT read out answers.</b></p> <p><i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p style="text-align: right;"><b><u>M</u> <u>NM</u></b></p> <p>Finding a job 1 2</p> <p>Having a baby 1 2</p> <p>Cure for HIV 1 2</p> <p>Children going to school 1 2</p> <p>Providing care for symptoms 1 2</p> <p>Staying healthy 1 2</p> <p>Drug treatment/methadone 1 2</p> <p>Emotional counseling 1 2</p> <p>Other: _____ 1 2</p> <p>Don't know 88</p> <p>No response 99</p>	

**SECTION 6: DRUG, ALCOHOL AND TOBACCO USE**

Now I would like to ask about drug, alcohol and tobacco use. Please remember you answers will be kept confidential. Please feel comfortable to tell us about your experiences with drugs, alcohol and tobacco.

***SECTION 6.1: INJECTING DRUG USE BEHAVIOR***

NO.	QUESTIONS AND FILTERS	CODING	
6.101	Have you ever injected illicit drugs (like heroin or opium) in your lifetime?	<p style="text-align: right;">Yes 1</p> <p style="text-align: right;">No 2</p> <p style="text-align: right;">No Response 99</p>	<b>→ 6.201</b>
6.102	Have you injected those drugs in the last 6 months?	<p style="text-align: right;">Yes 1</p> <p style="text-align: right;">No 2</p> <p style="text-align: right;">No Response 99</p>	<b>→ 6.201</b>
6.103	<p>During the last 6 months, which of the following drugs did you inject?</p> <p><b><i>SHOW NAMES OF DRUGS</i></b></p> <p><b>For each of the response choices, either '1' or '2' must be circled.</b></p>	<p><b>M = Mentioned</b></p> <p><b>NM = Not Mentioned</b></p> <p style="text-align: right;"><b><u>M</u> <u>NM</u></b></p> <p style="text-align: right;">Opium 1 2</p> <p style="text-align: right;">Heroin 1 2</p> <p style="text-align: right;">Amphetamines 1 2</p> <p style="text-align: right;">Anti-anxiety drugs 1 2</p> <p style="text-align: right;">Pain medicines 1 2</p>	

		Other _____ 1 2 No Response 99	
6.104	During the last week, how often have you injected drugs?  <b>Do NOT read out answers</b>  <i>Probe for response. Circle only one answer</i>	Never 1 1-2 times a week 2 3-4 times a week 3 Nearly every day 4 Every day 5 Don't know 88 No response 99	
<b>SECTION 6.2: SMOKING OPIOIDS; SMOKING CIGARETTES</b>			
<b>NO.</b>	<b>QUESTIONS AND FILTERS</b>	<b>CODING</b>	<b>SKIP TO</b>
6.201	How often did you smoke drugs in the last 6 months?  <i>Circle one response code number</i>	Never 1 1-2 times a month 2 1-2 times a week 3 Nearly every day 4 Every day 5 Don't know 88 No response 99	
6.202	Do you smoke cigarettes?  <i>Circle one response code number</i>	Yes 1 No 2 No response 99	
6.203	How many do you smoke on average in a day?  <i>Write in number</i>	_____ Number  Don't know 88 No response 99	
<b>SECTION 6.3: ALCOHOL USE</b>			
6.301	During the past one month how often have you had drink containing alcohol?  SHOW ANSWERS	Every Day 1 At least once a week 2 Less than once a week 3 Never 4 Don't know 88 No response 99	
6.302	Are there any services or support you feel you need for drug use or alcohol?  <b>Probe. Do NOT read out answers.</b> <i>(Multiple responses possible. After respondent answers, probe by asking for any others)</i>  <b>For each of the response choices, either '1' or '2' must be circled.</b>	Mentioned (M) Not mentioned (NM) <b><u>M NM</u></b> a) Needle&syringe exchange 1 2 b) Methadone 1 2 c) Relapse counseling 1 2 d) Alcohol use counseling 1 2 e) Other _____ 1 2  Don't know 88 No response 99	

<b>SECTION 7: Quality of Life</b>						
<p>The following questions ask how you feel about your quality of life, health, or other areas of your life. <b>There is no right or wrong answers and please choose the answer that appears most appropriate.</b> If you are unsure about which response to give to a question, the first response you think of is often the best one.</p> <p>Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life <b>in the last four weeks.</b> Please remember that your answers are entirely confidential.</p>						
NO.		Very Poor	Poor	Neither poor nor good	Good	Very good
7.101	How would you rate your quality of life?	1	2	3	4	5
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
7.102	How satisfied are you with your health?	1	2	3	4	5
<p>The following questions ask about <b>how much</b> you have experienced certain things in the last four weeks.</p>						
		Not at all	A little	A moderate amount	Very much	An extreme amount
7.103	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
7.104	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
7.105	How much do you enjoy life?	1	2	3	4	5
7.106	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7.107	How well are you able to concentrate?	1	2	3	4	5
7.108	How safe do you feel in your daily life?	1	2	3	4	5
7.109	How healthy is your physical environment?	1	2	3	4	5
<p>The following questions ask about how completely you experience or were able to do certain things in the last four weeks.</p>						
		Not at all	A little	Moderately	Mostly	Completely
7.110	Do you have enough energy for everyday life?	1	2	3	4	5

7.111	Are you able to accept your bodily appearance?	1	2	3	4	5
7.112	Have you enough money to meet your needs?	1	2	3	4	5
7.113	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
7.114	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
		<b>Very poor</b>	<b>Poor</b>	<b>Neither poor nor good</b>	<b>Good</b>	<b>Very good</b>
7.115	How well are you able to get around?	1	2	3	4	5
		<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither satisfied nor dissatisfied</b>	<b>Satisfied</b>	<b>Very satisfied</b>
7.116	How satisfied are you with your sleep?	1	2	3	4	5
7.117	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
7.118	How satisfied are you with your capacity for work?	1	2	3	4	5
7.119	How satisfied are you with yourself?	1	2	3	4	5
7.120	How satisfied are you with your personal relationships?	1	2	3	4	5
7.121	How satisfied are you with your sex life?	1	2	3	4	5
7.122	How satisfied are you with the support you get from your friends?	1	2	3	4	5
7.123	How satisfied are you with the conditions of your living place?	1	2	3	4	5
7.124	How satisfied are you with your access to health services?	1	2	3	4	5
7.125	How satisfied are you with your transport?	1	2	3	4	5
The following question refers to how often you have felt or experienced certain things in the last four weeks.						
		Never	Seldom	Quite often	Very often	Always
7.126	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

[The following table should be completed after the interview is finished]

Equations for computing domain scores			Raw score	Transformed scores*	
				4-20	0-100
7.127	<b>Domain 1: Physical health</b>	$(6-Q7.103) + (6-Q7.104) + Q7.110 + Q7.115 + Q7.116 + Q7.117 + Q7.118$	a. =	b:	c:
7.128	<b>Domain 2: Psychological</b>	$Q7.105 + Q7.106 + Q7.107 + Q7.111 + Q7.119 + (6-Q7.126)$	a. =	b:	c:
7.129	<b>Domain 3: Social relationships</b>	$Q7.120 + Q7.121 + Q7.122$	a. =	b:	c:
7.130	<b>Domain 4: Environment</b>	$Q7.108 + Q7.119 + Q7.112 + Q7.113 + Q7.114 + Q7.123 + Q7.124 + Q7.125$	a. =	b:	c:

\* Using the WHO Procedures Manual for score calculation

**Thank you very much for participating in this interview. We appreciate your time. The information you have provided us will help us to better understand how to improve care services so that you and others in the clinic will continue to get better and better care. Thanks so much and have a good day!**

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## Annex 3.2. English group interview guidelines for CHBC service providers

Respondent Group ID # \_\_\_\_\_

Date of interview (dd/mm/yy): \_\_\_\_\_

Type of Respondent: -----

Name of Interviewer: \_\_\_\_\_

### Read to the participant:

We are trying to understand the CHBC service providers' perception on the effectiveness of the Community and Home Based Care Services being provided by ASHA Project of FHI through various local organizations. In order to help us make sure the services are meeting the needs of service users, we would like to ask you about the services provided by CHBC team. The information you provide will be kept confidential and will only be used to improve our services. We do not need your name and neither will we share any of the information you provide to our program staff. We are interested in your honest opinion, whether they are positive or negative. Please express your views on all the issues discussed during this group interview and support us.

### Eligibility Criteria:

Individuals who are CHBC program managers and service providers (PLHIV or non-PLHIV) and who has been working in this profession for at least three months.

S.No.	Issues to be discussed during the group interview
1	Are there PLHIV in your working area? If yes, how many?
2	Do you know any specific services targeted to PLHIV in your working area? If yes what programs do you know?
3	In what context PLHIV come into your contact? How do you feel when they come in your contact? Do they come for any specific services/help? If yes what are they?
4	
5	A. Do you know who provides those CHBC services? Do you have any comments on the service? B. Do you collaborate with CHBC services? If so, how?
6	What do you understand by Quality of Life (QoL)? How do you rate your quality of life of PLHIV in your working area that you know?
7	Do you think that QoL of PLHIV whom you know has increased over time? If yes, tell me how it has been improved? Have you seen change in physical wellbeing? Who has helped for that?
8	Have you seen change in emotional problems? Who has helped for that?
9	Have you seen change in social wellbeing? Who has helped for that? Are you aware of various services that can be used by PLHIV? If yes tell me about it Do you think that CHBC services available are to be improved? If yes what improvements you can think of?
10	Think of those PLHIV whom you know, how frequently do they fall? How you or your organizations help them?
11	Do you keep informed about ongoing programs? If yes. You may have suggestions to them- can you share with us?
12	Do you think that family or community stigma and discrimination against PLHIV exists? If yes do you think your organization or any other programs can help it? If



	yes, how?
14	Do you think government of Nepal has been supporting CHBC program
15	How well does the structure of the current CHBC program meet needs of PLHA in your area?
16	Are the teams organized in way which maximizes use of resources and benefits to the clients. Are visits frequent enough? Are the teams over-burdened or could they take on more clients? Is there a balance between PLHA and health care workers in the team?
17	To what extent were CHBC services able to meet needs of clients? What are remaining gaps in service?
18	Why did the CHBC clients feel the service was useful to them?
19	Would like to add other things?

### Annex 3.3 English group interview guidelines for key informants

Respondent Group ID # \_\_\_\_\_ Date of interview (dd/mm/yy): \_\_\_\_\_  
 Type of Respondent: ----- Name of Interviewer: \_\_\_\_\_

**Read to the participant:**

We are trying to understand health worker’s and service provider’s perception on the effectiveness of the Community and Home Based Care Services being provided by ASHA Project of FHI through various local organizations. In order to help us make sure the CHBC services are meeting the needs of the CHBC service users, we would like to ask you about the services provided by CHBC team. The information you provide will be kept confidential and will only be used to improve our services. We will not share any of the information you provide to our program staff. We are interested in your honest opinion, whether they are positive or negative. We do not need your name. Please express your views on all the issues discussed during this interview and support us.

**Eligibility Criteria:**

Individuals who belong to one of the following category will be eligible for IDI interview:

- i. ART focal person    ii. DACC member    iii. PLHIV group members

S.No.	Issues to be discussed during group interview
1	Are there PLHIV in your working area? If yes, how many?
2	Do you know any specific services targeted to PLHIV in your working area? If yes what programs do you know?
3	In what context PLHIV come into your contact? How do you feel when they come in your contact? Do they come for any specific services/help? If yes what are they?
4	Have you heard about CHBC program? If yes what is CHBC program?
5	A. Do you know who provides those CHBC services? Do you have any comments on the service? B. Do you collaborate with CHBC services? If so, how?
6	What do you understand by Quality of Life (QoL)? How do you rate your quality of life of PLHIV in your working area that you know?
7	Do you think that QoL of PLHIV whom you know has increased over time? If yes, tell me how it has been improved? Have you seen change in physical wellbeing? Who has helped for that?
8	Have you seen change in emotional problems? Who has helped for that?
9	Have you seen change in social wellbeing? Who has helped for that?
	Are you aware of various services that can be used by PLHIV? If yes tell me about it Do you think that CHBC services available are to be improved? If yes what improvements you can think of?
10	Think of those PLHIV whom you know, how frequently do they fall? How you or your organizations help them?
11	Do you keep informed about ongoing programs? If yes. You may have suggestions to them- can you share with us?
12	Do you think that family or community stigma and discrimination against PLHIV exists? If yes do you think your organization or any other programs can help it? If yes, how?
13	Do you have anything else to add?
14	Do you think government are supporting CHBC program

### **Annex 3.4 English focus group discussion guidelines for caregivers of CHBC clients**

**Respondent Group ID #** \_\_\_\_\_ **Date of interview (dd/mm/yy):** \_\_\_\_\_

**Name of Interviewer:** \_\_\_\_\_

#### **Read to the participant:**

We are trying to understand CHBC client's caregiver's satisfaction with the Community and Home Based Care Services and their perception on the effectiveness of the program being provided by ASHA Project of FHI Nepal through various local organizations. In order to help us make sure the services are meeting your needs, we would like to ask you about the services you received at your home from the CHBC team. The information you provide will be kept confidential and will only be used to improve our services. We will not record your name and neither will we share any of the information you provide to our program staff. We are interested in your honest opinion, whether they are positive or negative. Please express your views on all the issues discussed during this focus group discussion and support us.

#### **Eligibility Criteria:**

Caregivers of PLHIV of age 18 or above who has been receiving CHBC services provided by the ASHA Project supported programs since last six months or more.

#### **Topics to be discussed:**

1. Caregivers' perception on the current Community and Home Based Care
2. Any formal training in caring for PLHIV from any NGO
3. Informal education during the home visit by CHBC team
4. Important things that you learnt during the training or home visit
5. Knowledge on why PLHIV need to go for regular check ups at ART sites?
6. Observation of any symptoms of other illness in caregiver's spouse/friend/ children who is a PLHIV. If so, discuss on home remedies provided for symptoms and ailments like diarrhea, fever, oral sore, skin problem and bed care.
7. Response on stigma and discrimination in the community
8. Support to family or spouse/ PLHIV in the community?
9. Type of support and care given to improve the health of the PLHIV whom you are caring for.
10. Knowledge on nutrition and hygiene
11. Knowledge on importance of ART adherence among PLHIV
12. Availability of community support in a case of an emergency
13. Need for family network to support each other and if so, discuss on ways to form support groups within the community
14. Suggestions on additional support that CHBC and government of Nepal should provide to families and households affected by HIV

### **Annex 3.5. English focus group discussion guidelines for PLHIV CHBC clients**

**Respondent Group ID #** \_\_\_\_\_ **Date of interview (dd/mm/yy):** \_\_\_\_\_

**Name of Interviewer:** \_\_\_\_\_

#### **Read to the participant:**

We are trying to understand client's satisfaction with the Community and Home Based Care Services and their perception on the effectiveness of the program being provided by ASHA Project of FHI Nepal through various local organizations. In order to help us make sure the services are meeting your needs, we would like to ask you about the services you received at your home from the CHBC team. The information you provide will be kept confidential and will only be used to improve our services. We will not record your name and neither will we share any of the information you provide to our program staff. We are interested in your honest opinion, whether they are positive or negative. Please express your views on all the issues discussed during this focus group discussion and support us.

#### **Eligibility Criteria:**

PLHIV of age 18 or above who has been using CHBC services provided by the ASHA Project supported programs since last six months or more.

#### **Topics to be discussed:**

- 1) Visits by the CHBC service provider – by appointment, communicates respectfully frequency, total time spent etc
- 2) Experience in interaction with CHBC service providers
- 3) Issues related to disclosure of HIV status
- 4) Services received through CHBC program
  - a. Education on nutrition, hygiene, positive prevention, safe sex, safe injecting practice etc
  - b. Regular health check-up for symptoms
  - c. Treatment for symptoms and clear instructions on taking medication and next appointment for follow up at ART clinic
- 5) Care and support received on issues besides health problems
- 6) Referrals provided for health service, HIV testing, FP , PMTCT, social support, schooling and satisfaction with referral
- 7) CHBC team addresses needs of the whole family
- 8) Experiences with stigma and discrimination and coping skills
- 9) Attendance for continuity of care – frequency of visit in ART/EPC
- 10) ART adherence (if on ART) including cotrim , TB drugs
- 11) CHBC service providers self care and positive living counseling
- 12) Perceptions of health and wellbeing after receiving CHBC
- 13) CHBC service providers interaction with respondent's family members, children and caregivers
- 14) Degree of family and other social support
- 15) Provides emotional, spiritual needs and counseling
- 16) Membership in PLHIV support group
- 17) CHBC team members make appointment for follow up visit
- 18) Client's feel that CHBC team visit their home for support with adequate frequency
- 19) Recommend CHBC services to other infected and affected families

### Annex 3.6. CHBC QA/QI Checklist

#### FHI Nepal CHBC Program Assessment

Name of Health Facility:

Assessment team member:

Date:

1. Training	Method	Yes	No	Remarks
1.1 CHBC teams have been trained/certified by MoH, FHI or an organization approved by FHI.	MI			
1.2 CHBC teams have received or will receive training in caring for children living with and affected by HIV by MoH, FHI or an organization approved by FHI.	MI			
1.3 CHBC teams have been provided a technical overview in areas appropriate to client population (e.g., drug use, harm reduction, substitution therapy; needs of MSM, SWs, youth; reproductive health, including family planning and PMTCT).	MI			
1.4 CHBC teams are receiving on-the-job mentoring and support and refresher training	MI			

2. Program planning and approach	Method	Yes	No	Remarks
2.1 HIV care needs are assessed regularly and CHBC service map is updated regularly.	MI			
2.2 CHBC services are voluntary: CHBC is only provided to PLHA or family who request the service.	SI			
2.3 The service is family centered: the design of the CHBC program is family centered and includes provision of care to children.	S/I			
2.4 CHBC service is offered in a clearly defined geographic area.	SI			

<b>2. Program planning and approach</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
2.5 CHBC is linked to EPC /ART and PMTCT hospital	S/I			
2.6 Community mobilization: Community resources are being contributed to the CHBC program (e.g., labor, food, support for funerals, donations, etc.).	SI/MI			

<b>3. Management and administration</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
2.7 Community resources are being contributed to the CHBC program (e.g., labor, food, support for funerals, donations, etc.).	MI			
3.1 A system is in place to cross-train staff/volunteers to ensure CHBC team members can be replaced efficiently.	MI			
3.2 All staff members have signed the “Oath of Confidentiality”. The documents are available to the review team.	MI			
3.3 There is a designated CHBC supervisor. The supervisor routinely observes and mentors CHBC teams. The supervisor uses supervision checklists and provides feedback to staff on performance.	MI			
3.4 Written procedures (SOPs) detailing how the CHBC services are to be implemented are accessible to all relevant staff. Managers and staff have been trained on these procedures.	MI/SI			
3.5 Staff and volunteers <u>report</u> that they are receiving ongoing mentoring, encouragement, supportive supervision to fulfill their responsibilities from supervisors and team members.	MI/SI			
3.6 Program reports, including service coverage indicators, are filed and readily available for review.	MI			
3.7 Targets have been set for key performance indicators (e.g., number of people receiving services).	MI/SI			
3.8 Performance against targets is reviewed by managers and staff. The number of CHBC clients served during last month meets or exceeds	MI/SI			

<b>3. Management and administration</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
targets.				
3.9 It is made clear to CHBC staff that CHBC is a <u>voluntary service</u> . Although targets might have been set, they cannot violate client rights to choose CHBC to meet that target.	MI/SI			
3.10 All CHBC teams have had Hepatitis B serology checked and if negative have been offered vaccination.	MI/SI			
3.11 PEP, HIV care and ART are available to all staff/volunteers with occupational exposure to HIV, and are provided free of charge.	MI/SI			

<b>4. General operational issues</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
4.1 The CHBC team has a base/office where they meet, rest, keep files, and store medicines and other consumables. The space includes basic facilities (e.g., toilets, running water).	MI/SI			
4.2 Essential referral relationships have been established with a HIV care and treatment outpatient clinic, TB services, inpatient care and other services ( RH/FP, income-generation services, schools).	MI/SI			
4.3 Referral forms are available and used by CHBC team members.	MI/SI			
4.4 A service referral directory is available and was updated in the last year.	MI/SI			
4.5 CHBC staff members have a means of communication with referral sites and teams (e.g., phone, email and internet access).	MI/SI			
4.6 There is an 'on-call' system in place where clients can contact a member of the CHBC in the event of an emergency.	MI/SI			
4.7 If relevant, CHBC teams participate in regular case review meetings	MI/SI			

<b>4. General operational issues</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
with the outpatient clinic/hospital they are linked with in order to improve quality of coordination, follow-up and referrals.				

<b>5. Infection control practices</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
5.1 Masks and gloves are available to CHBC team and are being used correctly.	MI/SI			
5.2 There is a first aid box in the office which is available to staff, including simple methods for eye washing, covering of cuts and lesions.	MI/SI			
5.3 PEP is available on site or close by, an algorithm describing management of an exposure is present and staff members are trained in PEP. PEP register is maintained and updated.	MI/SI			
5.4 Procedures exist for the safe disposal of all waste (incineration and dumping) in accordance with MoH standards.	MI/SI			
5.5 Instruments are cleaned with clean water and detergent.	MI/SI			
5.6 Sodium hypochlorite solution or chlorine solution is available and prepared at the right strength (e.g., 0.5% for chlorine solution).	MI/SI			

<b>6. CHBC records and client registration</b>	<b>Method</b>	<b>Yes</b>	<b>No</b>	<b>Remarks</b>
6.1 Standard FHI-approved client registration and filing system (that maintains confidentiality) is in place and being maintained at all times.	MI/SI			
6.2 Files are kept in a locked cabinet. Access to files is limited to only those designated. A coding system is used so that names of clients are protected.	MI/SI			
6.3 There is evidence that CHBC teams promptly and completely fill in 'client first visit' and 'follow-up visit' forms.	MI/SI			
6.4 CHBC client folders are coded and filed in an organized manner. There is a system for managing active and inactive files (e.g., files of	MI/SI			



6. CHBC records and client registration	Method	Yes	No	Remarks
individuals who have died, who are lost to follow up or who have been discharged from the service).				
7. CHBC supplies	Method			
7.1 CHBC teams have a home care kits (bag of essential care supplies). The kits are stored in a safe and dry place, and are replenished as needed.	O			
7.2 CHBC kit is contained in a bag selected by the CHBC team that is comfortable to carry (e.g., a backpack).	O			
7.3 CHBC kits contain a standard set of symptom care medicines and supplies approved by MoH/FHI.	O			
7.4 Where care is provided to children, the kits contain medicines appropriate to them.	O			
7.5 Home care supplies are consistently available. No stock-outs have been reported in the past 3 months.	MI/SI			
7.6 CHBC teams are trained to use the medicines and supplies in the kit.	MI/SI			
7.7 Home-care teams have access to the following medicines and supplies: <i>This list must be adapted to the needs of clients and available medicines in each area.</i>	MI/SI			
7.7.1 Sterile disposable gloves	O			
7.7.2 Masks	O			
7.7.3 Soap for hand washing	O			
7.7.4 Sterilizing fluid for cleaning equipment, blood spills	O			
7.7.5 Analgesics for mild pain ( <u>combination of a few</u> e.g., paracetamol, aspirin, ibuprofen, diclofenac)	O			

7. CHBC supplies	Method			
7.7.6 Analgesics for moderate pain [paracetamol/ codeine (500mg/30mg),	O			
7.7.7 Tinidazole 1 Gm or Metronidazole 400 mg.,	O			
7.7.8 Domperidone	O			
7.7.9 Hyoscine 10 mg e.g. (Buscopan) or Drotaverine 40 mg (Drotin)	O			
7.7.10 Antifungal lozenge, pessary and cream (e.g., clotrimazole, miconazole, nystatin)	O			
7.7.11 Antifungal solution (gentian violet)	O			
7.7.12 Constipation e.g., (Dulcolax)	O			
7.7.13 Gentian Violet	O			
7.7.14 Scabicide (e.g., benzyl benzoate, permethrin)	O			
7.7.15 Petroleum jelly/vaseline	O			
7.7.16 Calamine lotion	O			
7.7.17 Zinc oxide talcum powder	O			
7.7.18 Medicated balm	O			
7.7.19 Rubbing alcohol	O			
7.7.20 Hydrogen peroxide	O			
7.7.21 Povidine iodine	O			
7.7.22 Multivitamin	O			
7.7.23 Vitamin B complex	O			
7.7.24 ORS	O			
7.7.25 Condoms	O			

<b>7. CHBC supplies</b>	<b>Method</b>			
7.7.26 Sphygmomanometer and Stethoscope	O			
7.7.27 Wound dressing sets	O			
7.7.28 Scissors, tweezers and container for sharps	O			
7.7.29 Tongue depressors, flashlight and back-up batteries	O			
7.7.30 Plastic bags for refuse and materials for disposal at facility	O			
7.7.31 Self-care information (self-care book, pamphlets, etc.)	O			
7.7.32 National service information (e.g., harm reduction, OVC/CABA care)				

<b>8. Home-based care visits</b>	<b>Method</b>			
<b>8.1 General home visit planning</b>				
8.1.1 CHBC program has formally defined what services it will and will not offer. It has communicated these limitations to partners and clients.	S/I			
8.1.2 Client visits are made with optimum frequency (e.g., once a week) to ensure continuity of care and prevent neglect.	S/I			
<b>8. Home-based care visits</b>				
8.1.3 Clients are prioritized. Those with greater care needs are visited with greater frequency than those who only require routine visits.	S/I			
8.1.4 Clients are visited by the same team to promote stable and continuous care.	S/I			
8.1.5 There is a weekly/ monthly home visit plan in place. Teams plan and schedule home visits together..	S/I			
<b>8.2 Home visit observation</b>				
8.2.1 CHBC members are well prepared and bring appropriate supplies according to patient needs.	O			

8.2.2	CHBC teams make appointments with client and family. Client and family know the CHBC team is coming.	O			
8.2.3	CHBC team greets clients and family in an appropriate manner, including introduction of CHBC team members and observers.	O			
8.2.4	CHBC members do not ignore PLHA, family or children and communicate respectfully and clearly with them. Attempts are made to make PLHA and family comfortable with every visit.	O			
8.2.5	CHBC members start the visit by enquiring after the needs of PLHA and family, and following up on previously identified needs. CHBC members conduct a holistic assessment, asking about physical, emotional, social and spiritual needs.	O			
8.2.6	When caring for families, the CHBC team addresses needs of the whole family, not just the individual with HIV (family-centered care).	O			
<b>8.2</b>	<b>Home visit observation</b>				
	<i>Physical care and support</i>				
8.2.7	CHBC team member takes client history: asks about new signs or symptoms (e.g., pain, symptoms and side effects).	O			
8.2.8	CHBC team member checks doctor's prescription or ART booklet of previous clinic visits, medicines prescribed and next clinic appointment.	O			
8.2.9	CHBC team member reviews new and old medicines being taken; asks to see medicines; clarifies what each is being taken for; and checks how well the client understands their prescriptions.	O			
8.2.10	CHBC team member washes hands before/after providing care and takes other infection prevention measures, as appropriate (e.g., gloving).	O			
8.2.11	CHBC team member takes vital signs (pulse, temperature, respiration, BP), informs PLHA of the results and documents them in client file.	O			
8.2.12	CHBC team member asks client if they have pain and uses pain scale to determine the severity of pain (e.g., 0-10 or another scale). Results	O			

are documented in the client file.				
8.2.13 CHBC team member does basic physical exam: examines eyes, mouth, tongue, lymph nodes, abdomen, skin and genitals (as appropriate).	O			

<b>8.2 Home visit observation</b>	O			
8.2.14 CHBC team member discusses exam findings with client and family, and explains the care they will provide.	O			
8.2.15 CHBC team member provides care (appropriate to findings) to PLHA (manages pain, bed sores and other symptoms).	O			
8.2.16 CHBC team member teaches PLHA/family how to manage problems identified and when to refer.	O			
8.2.17 CHBC team member provides care supplies needed to manage problem identified.	O			
8.2.18 ART , TB and cotimoxazole prophylaxis adherence: CHBC team member asks client about ability to adhere to medicines.	O			
8.2.19 If client is bed-bound, CHBC team member teaches family how to clean and care for skin and change position to prevent bed sores; how to provide bowel and bladder care; and how to feed, hydrate and comfort client.	O			
8.2.20 If client is near end of life, CHBC team member provides responsive and appropriate end-of-life care (pain, symptoms, skin care; counseling, preparations).	O			
8.2.21 CHBC team member assesses availability to and intake of food and clean water, and if the client is able to eat three balanced meals a day.	O			
8.2.22 CHBC team member provides self-care and positive living counseling , as appropriate.	O			

<b>8.2 Home visit observation</b>	O			
8.2.23 CHBC team member uses available educational tools (the self-care series books, nutrition brochure, ART brochure, side effect brochure, O/I brochure ) to promote self-care skills and self-reliance of clients, and provides such tools to the client, as appropriate.	O			
8.2.24 CHBC team member provides information on safer sex, family planning, PMTCT, harm reduction, as needed.	O			
<i>Emotional, social and spiritual support</i>	O			
8.2.25 CHBC team member assesses client's and families' emotional, social and spiritual needs.	O			
8.2.26 CHBC team member provides emotional support, including active listening, empathy and active problem solving.	O			
8.2.27 CHBC team member helps client and family to prepare a social, emotional, spiritual support plan.	O			
8.2.28 If appropriate, CHBC team member arranges for follow-up counseling with client/family.	O			
8.2.29 In case of danger signs (intention of harm to self/others), CHBC team member provides support and arranges for additional help to client/family.	O			
8.2.30 CHBC team member refers client and family to PLHA and family support groups if they are not already members.	O			
<i>Safer sex, family planning and PMTCT</i>	O			
8.2.31 As relevant, CHBC team member provides client with basic information on safer sex, family planning, PMTCT and on how to access services.	O			
8.2.32 If not already seeking care at an ART clinic /EPC, CHBC team member provides information on clinics and actively supports referral if client opts to go.	O			
8.2.33 For female/couple clients wanting to be or already pregnant, CHBC team member provides information on benefits of PMTCT service	O			

<b>8.2 Home visit observation</b>	O			
and actively supports referral to service if clients opt to go.				
8.2.34 CHBC team member provides supportive counseling, including assistance with partner disclosure and coping with partner reaction.	O			
8.2.35 For women/couples enrolled in PMTCT program, CHBC team member reviews clinic visit schedule and provides support if needed in attending routine clinics.	O			
8.2.36 CHBC team member asks about PMTCT ARV and cotrimoxazole adherence and side effects, and provides support.	O			
8.2.37 CHBC team member asks about other routine ANC support (access to Fe & Folic Acid, TT, etc.) and provides referral to ANC services as needed.	O			
8.2.38 CHBC team member checks for pregnancy-related danger signs as part of overall history and exam taking: hemorrhaging, swollen legs, dizziness, anemia, etc.	O			
8.2.39 CHBC team member visits family just after delivery to provide continuity of care.	O			
8.2.40 CHBC team member checks for post-partum danger signs: P/V bleeding, infection, anemia, etc.	O			
<i>If caring for an HIV-exposed child and or un known status</i>	O			
8.2.41 CHBC team member checks for danger signs; refers if danger signs identified.	O			
8.2.42 If < age 5, CHBC team member checks growth monitoring ( IMCI) Immunization card , doctor's prescription of previous clinic visits, medicines prescribed and next clinic appointment.	O			
8.2.43 CHBC team member assesses infant feeding, counsels mother/caregiver about dangers of mixed feeding and provides support for either exclusive breast or exclusive formula feeding.	O			
8.2.44 CHBC team member asks about cotrimoxazole adherence, side-effects and provides support; , does a pill count, etc.; helps family	O			

<b>8.2 Home visit observation</b>	O			
manage adherence; and refers child to the clinic if problems with adherence are identified.				
8.2.45 CHBC team member provides information on HIV testing for infants and support in accessing HIV counseling and testing if the family opts for it.	O			
8.2.46 CHBC team member assesses availability to food and nutritional intake, and makes plan to address any barriers to food for client and family.	O			
8.2.47 CHBC team member asks about use of/access to national nutrition supplies/services (e.g., multi-vitamin syrup, deworming, Supplemental feeding and WFP food packages	O			
8.2.48 CHBC team member assesses physical, emotional, social, cognitive and spiritual needs of children, and provides care and support as relevant, including: future planning, wills, foster care placement, emotional support, and cognitive development, including play, nutrition and health care.	O			
8.2.49 CHBC team member arranges for referrals to supportive services.	O			
8.2.50 CHBC team member refers child to play group activities (or other early childhood development programs), if appropriate.	O			
<i>If caring for HIV+ child</i>	O			
8.2.51 CHBC team member checks for danger signs (general childhood and HIV-related illness); and promptly refers child if danger signs are identified.	O			
8.2.52 CHBC team member checks the EPC/ ART prescription of previous clinic visits, medicines prescribed and next clinic appointment.	O			
8.2.53 CHBC team member assesses infant feeding, counsels mother/caregiver about dangers of mixed feeding and provides support for either exclusive breast or exclusive formula feeding.	O			
8.2.54 CHBC team member asks about cotrimoxazole, TB and ART	O			



<b>8.2 Home visit observation</b>	O			
adherence, side-effects and provides support; checks the level of understanding of the caregiver in how ART, cotrim, TB and other medication should be taken by the child; as per national adherence protocol, does a pill count, checks medicine calendar, pill boxes, etc.; helps family manage complicated adherence (e.g., taking medicines at school); and refers child to ART clinic if problems with adherence are identified.				
8.2.55 If < age 5, CHBC team member checks yellow IMCI growth monitoring and immunization card (ensures child is getting immunizations on schedule, growing well, etc.).	O			
8.2.56 CHBC team member assesses availability to food and nutritional intake, and develops a plan to address any barriers to food for client and family.	O			
8.2.57 CHBC team member asks about use of/access to national nutrition supplies/services (e.g., multi-vitamin syrup, deworming, supplemental feeding, WFP food packages).	O			
8.2.58 CHBC team member assesses needs of children and provides care and support as relevant (future planning, wills, foster care placement, emotional support, cognitive development, including play, schooling support, nutrition and health care).	O			
8.2.59 CHBC team member informs family of available support services (e.g., play groups for children > 3 yrs of age; family caregiver support groups; youth groups, etc.).	O			
8.2.60 CHBC team member arranges for referrals to supportive services as needed.	O			
8.2.61 CHBC team member refers child to play group activities (or other early childhood development programs), if appropriate.	O			
	O			
<i>End of home visit/follow up</i>	O			
8.2.62 CHBC team member asks if the client/family have any remaining	O			

<b>8.2 Home visit observation</b>	O			
needs or questions.				
8.2.63 CHBC team member summarizes main findings and main actions to be taken with client and family, and checks with client and family to ensure that they agree with findings and next steps.	O			
8.2.64 CHBC team member makes appointment for follow-up visit with client and reminds client of upcoming clinic appointments.	O			
8.2.65 CHBC team member debriefs with supervisor and/or OPC clinic staff if any issues were raised that CHBC team was unable to address.	O			
8.2.66 CHBC team member correctly documents and files report in locked cabinet.	O			
8.2.67 CHBC team member replenishes CHBC kits as needed.	O			
<b>9. Community services</b> (assess if relevant to program)	O			
<b>9.1 Community mobilization/awareness building</b>	O			
9.1.1 Community awareness activities are organized with adequate frequency to contribute to changes in knowledge among community members.	O			
9.1.2 There is evidence of community involvement and ownership of the program.	O			
9.1.3 Where community barriers to PLHA accessing support and services exist, the CHBC program is strategically addressing such barriers.	O			
<b>9.2 Community care</b>	O			
9.2.1 CHBC teams provide care to homeless, migrant/mobile PLHA, not wanting or able to receive care in the home, in the community or at other locations (e.g., drop-in center, shelter, hospice, crisis center).	O			
9.2.2 CHBC teams meet clients at their preferred location and optimize privacy for clients given the environment of care (street, park, etc.).	O			
9.2.3 CHBC teams follow procedures under <i>II. Home-based care visits</i>	O			

<b>8.2 Home visit observation</b>	O			
when assessing needs and providing care.				
9.2.4 CHBC teams support client to access a stable living environment if that is what the client wants.	O			
9.2.5 For homeless, migrants/mobile populations, CHBC teams work with others to address shelter needs.	O			
9.2.6 CHBC teams assist client in reuniting with family, if that is what client wants.	O			

<b>10. Monitoring and evaluation</b>	<b>Method</b>			
<b>10.1 Client satisfaction</b>				
10.1.1 Clients feel confidentiality is being maintained by CHBC team.				
10.1.2 Clients feel that they are being treated with respect and dignity by CHBC team.				
10.1.3 Clients feel CHBC team comes to their home for support with adequate frequency				
10.1.4 Clients report satisfactory experiences with referral services.				
<b>10.2 CHBC reporting and data collection</b>				
10.2.1 Data collection forms are available in project files and used correctly.	O			
10.2.2 Data collected at each level of staff is correct and complete.	O			
10.2.3 Reports (monthly/quarterly) are completed and submitted to FHI as scheduled for the past three months. FHI Project monitor responds within one month.	O			
10.2.4 CHBC teams understand what is being measured by report forms and how to collect the data.	O			
10.2.5 CHBC teams participate in/lead data analysis and in using findings to	O			

<b>10. Monitoring and evaluation</b>	<b>Method</b>			
adapt the program.				
10.2.6 A process is in place for routine and participatory team analysis of program data.	O			
<b>10.3 CHBC QA/QI and evaluation</b>				
10.3.1 Routine program process evaluation is conducted which includes QA/QI.	MI			

## Annex 4: Sample size Formula for Objective 3

The formula used for the calculation of sample size for the comparison of two proportions is given below.

$$n = D \frac{\left[ \sqrt{2P(1-P)}Z_{1-\alpha} + \sqrt{P_1(1-P_1) + P_2(1-P_2)}Z_{1-\beta} \right]^2}{\Delta^2}$$

Where

- D = design effect
- $P_1$  = the known/assumed value of the indicator of interest or the estimated proportion of the target population that has the characteristic of interest at the time of the survey (control group)
- $P_2$  = the value of the indicator of interest in the treatment group such that the quantity ( $P_2 - P_1$ ) is the magnitude of change one desires to be able to detect
- $P = (P_1 + P_2)/2$
- $Z_{1-\alpha}$  = the z-score corresponding to the probability with which one desires to be able to conclude that an observed change of size ( $P_2 - P_1$ ) would not have occurred by chance. Use  $\alpha/2$  if a two-sided test is planned
- $Z_{1-\beta}$  = the z-score corresponding to the degree of confidence with which one desires to be certain of detecting a change of size ( $P_2 - P_1$ ) if one actually occurred
- $\Delta = (P_2 - P_1)$ , the minimum difference between groups worth detecting

Sample size for the study was calculated based on  $D = 1$ ,  $P_1 = 0.85$ ,  $P_2 = 0.95$ ,  $Z_{1-\alpha} = 1.96$  at 95% S.L.,  $Z_{1-\beta} = 0.84$  for 80% power and  $\Delta = (P_2 - P_1) = 10\%$  difference, a sample size of 140 in each arm totaling to 280 sample size for both program and control groups is estimated.

Given the literature shows a high percentage of symptoms in PLHIV – averaging 95% and that a similar intervention study contributed to the reduction of symptoms to 85%, the sample size was calculated based on 95% pain prevalence in the control and 85% in the intervention arm.